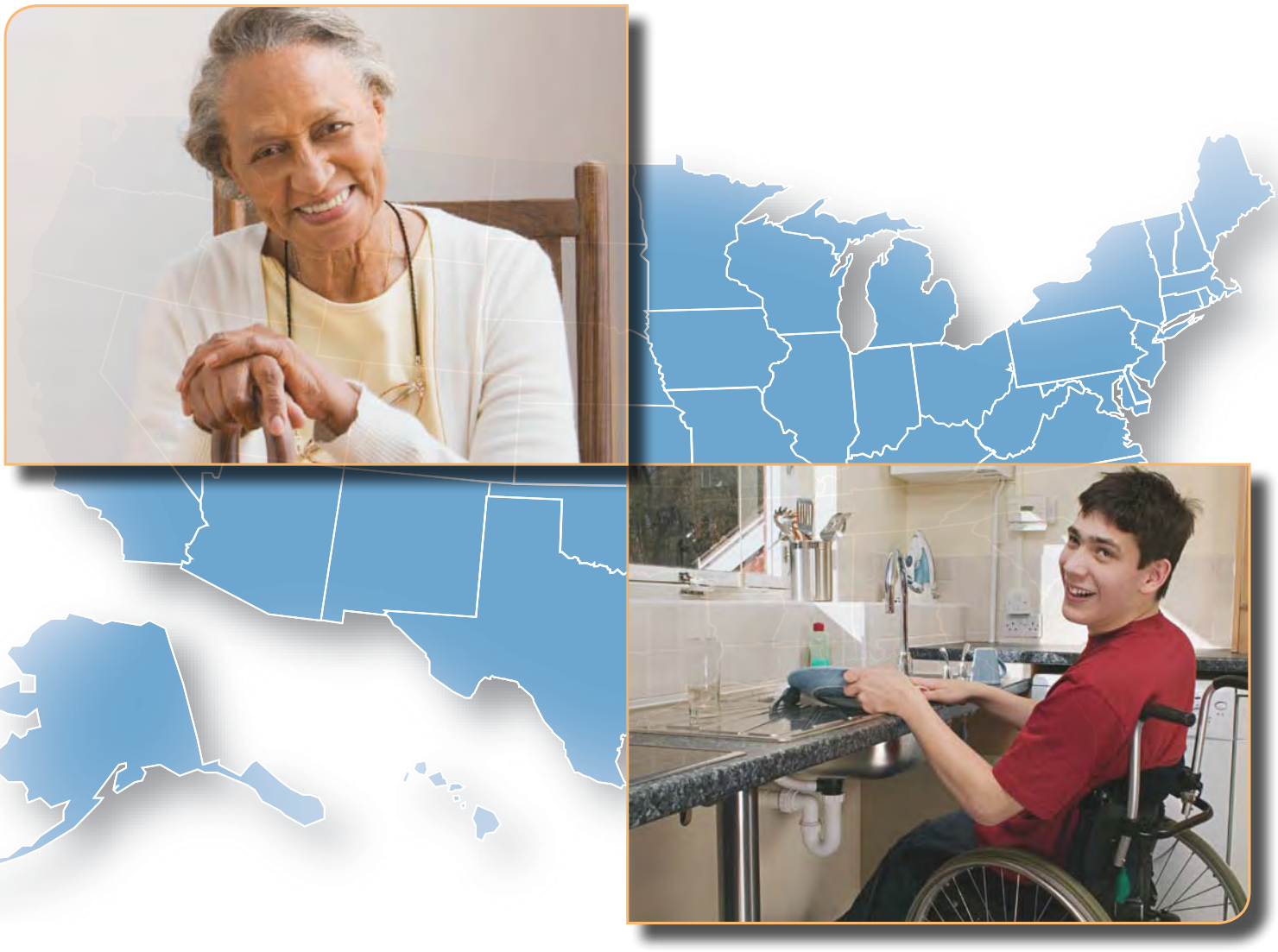
Raising Expectations

A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers

Susan C. Reinhard, Enid Kassner, Ari Houser, and Robert Mollica

September 2011



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ABSTRACT

This *State Long-Term Services and Supports (LTSS) Scorecard* is the first of its kind: a multidimensional approach to measure state-level performance of LTSS systems that provide assistance to older people and adults with disabilities. Performance varies tremendously across the states with LTSS systems in leading states having markedly different characteristics than those in lagging states. Yet even the top-performing states have some opportunities for improvement.

The *Scorecard* examines state performance across four key dimensions of LTSS system performance: (1) affordability and access; (2) choice of setting and provider; (3) quality of life and quality of care; and (4) support for family caregivers. It is designed to help states improve the performance of their LTSS systems. It also underscores the need for states to develop better measures of performance over a broader range of services and collect data to more comprehensively assess the adequacy of their LTSS systems.

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PREFACE

The AARP Foundation, The Commonwealth Fund, and The SCAN Foundation are pleased to sponsor this first *State Long-Term Services and Supports (LTSS) Scorecard* in the hope that it will help meet the growing need for comparative analysis of state LTSS systems and contribute to positive action among the states. Long-term services and supports for frail older people and people with disabilities span a range that includes home care, adult day care, residential services such as assisted living, and nursing homes. They also provide respite care and other support for family caregivers. For those with low or modest incomes, public financing of programs that provide LTSS facilitates access to services that would otherwise be unaffordable.

LTSS are a growing concern for older adults, people with disabilities, and their families in the United States. Most Americans will eventually access the LTSS system, either as consumers of LTSS or as caregivers who provide support to family members and friends. Despite the widespread personal experience with LTSS and the challenges it presents for both users and their families, it is difficult to find comprehensive information about the performance of national and state-level LTSS systems.

It is impossible to discuss national reform of LTSS without examining how services are currently financed and delivered in the states. Even with the historic passage of the *Affordable Care Act*, states will continue to play important roles in shaping the choices available to consumers and their families, paying for services to low-income individuals, and overseeing the quality of the services provided. These issues are intensified by the fact that states are facing increased budget reductions, which makes the allocation of resources even more compelling.

It is therefore an opportune time to provide state officials with a snapshot of their state's performance within a national context. Our vision of a high-performing LTSS system is an achievable goal for each state and for the country as a whole, but will require action by both state and national leaders. This *Scorecard* will provide those leaders with the information they need to evaluate their current performance and establish more effective policies to give millions of Americans the future they deserve.

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EXECUTIVE SUMMARY

This *State Long-Term Services and Supports Scorecard* is the first of its kind: a multidimensional approach to measure state-level performance of long-term services and supports (LTSS) systems that provide assistance to older people and adults with disabilities. Analysis of the "starter set" of indicators included in this report finds that performance varies tremendously across the states with LTSS systems in leading states having markedly different characteristics than those in lagging states. Yet even the top-performing states have some opportunities for improvement. In general, the states at the very highest levels of performance have enacted public policies designed to:

- improve access to needed services and choice in their delivery by transforming their Medicaid programs to cover more of the population in need and offer the alternatives to nursing homes that most people prefer;
- facilitate access to information and services by developing effective "single point of entry" systems so that people who need services can find help easily; and
- address the needs of family caregivers by offering legal protections as well as the support and services that can help prevent burnout.

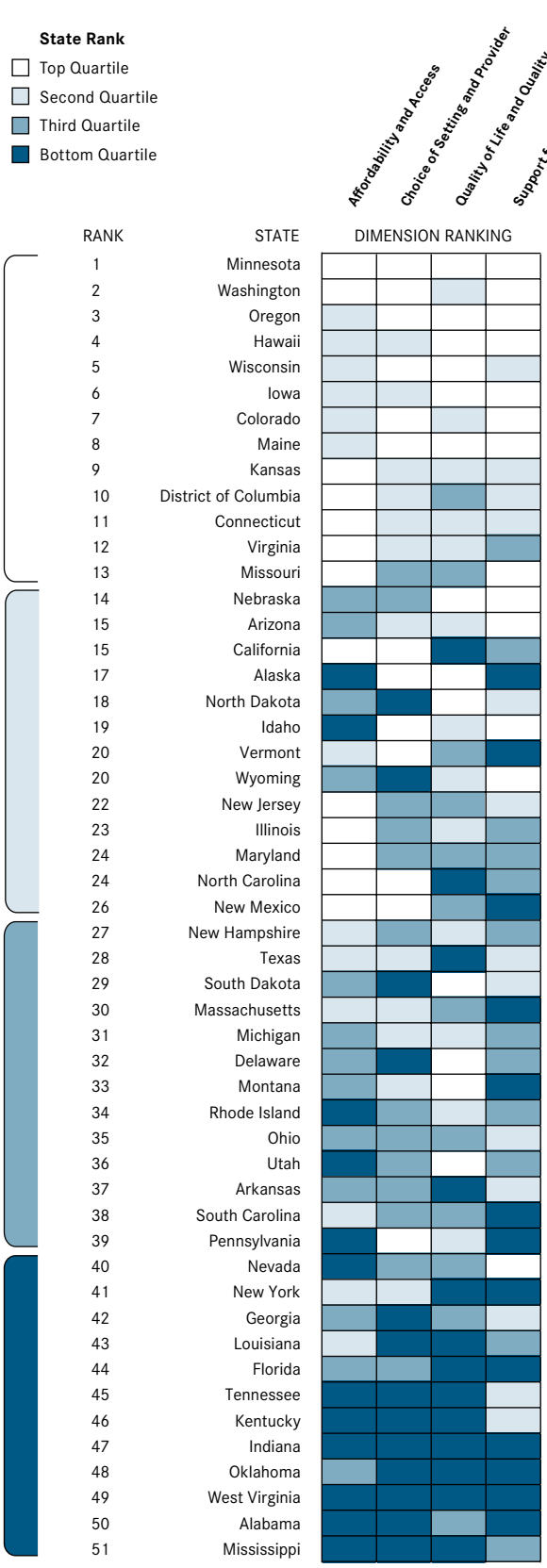
Public policy plays an important role in LTSS systems by establishing who is eligible for assistance, what services are provided, how quality is monitored, and the ways in which family caregivers are supported. Its role is especially critical because the cost of services exceeds the ability to pay for most middle-income families. Even in the most "affordable" states, the cost of nursing home care exceeds median income for the older population. Thus, states need to take action to ensure that alternatives to nursing homes are available, an effective safety net helps people who are not able to pay for care, and family caregivers, who provide the largest share of help, receive the support they need. States also have a leading role to play in ensuring that the LTSS delivered in all settings are of high quality. But public policy is not the only factor affecting state LTSS performance: actions of providers and other private sector forces affect state performance either independently, or in conjunction with the public sector.

The *Scorecard* is designed to help states improve the performance of their LTSS systems so that older people and adults with disabilities in *all* states can exercise choice and control over their lives, thereby maximizing their independence and well-being. Our intention is that this *Scorecard* will begin a dialogue among key stakeholders so that lagging states can learn from top performers and all states can target improvements where they are most needed. Furthermore, we hope that the *Scorecard* will underscore the need for states to develop better measures of performance over a much broader range of services and collect data in order to more comprehensively assess the adequacy of their LTSS systems.

The *Scorecard* examines state performance across four key dimensions of LTSS system performance, developed in consultation with a team of expert advisors: (1) affordability and access; (2) choice of setting and provider; (3) quality of life and quality of care; and (4) support for family caregivers. Exhibit 1

Exhibit 1

State Scorecard Summary of LTSS System Performance Across Dimensions



Source: State Long-Term Services and Supports Scorecard, 2011.

illustrates each state's overall ranking as well as its quartile of performance in each of the four dimensions. These four dimensions align with the characteristics of a high-performing LTSS system as recently articulated by the authors in *Health Affairs*.[1] We identified a fifth dimension, coordination of LTSS with medical services, which is also critically important but were unable to create indicators to measure that dimension with currently available data. Indeed as we discuss below, one of the more noteworthy "findings" of our work on the *Scorecard* is how much we are not able to compare because information on quality, experiences, coordination, costs, or outcomes is simply not available. Information is critical to guide and inform improvement. We hope that this *LTSS Scorecard* will spark future federal and state action.

Within the four dimensions, the *Scorecard* includes 25 indicators. Exhibit 2 lists the indicators that compose each dimension and shows the range of performance across the states for each indicator. While some of the indicators rely on data that have been reported elsewhere, many represent new measures. Several indicators are constructed from a range of data in a related area, facilitating the ability to rank states in areas of performance that are difficult to assess. As such, the findings differ from analyses that examine a single aspect of states' LTSS systems, such as the "balance" of public services provided in home- and community-based settings compared to nursing homes. This multidimensional analysis involves a richer exploration of data to assess performance, thereby capturing state performance across a complex range of system characteristics.

Major Findings

The states that ranked at the highest level across all four dimensions of LTSS system performance, in order, are Minnesota, Washington, Oregon, Hawaii, Wisconsin, Iowa, Colorado, and Maine.

Leading states often do well in multiple dimensions—but all have opportunities to improve

The leading states generally score in the top half of states across all dimensions. Public policy decisions made in these states interact with private sector actions, resulting in systems that display higher performance. But no state scored in the top quartile across all 25 indicators, demonstrating that every state LTSS system has at least one indicator on which it trails the standards set by top states. Even within dimensions, there is only one instance in which a state ranked in the top quartile across every indicator in the dimension.

Poverty and high rates of disability present challenges

Lagging states scored in the bottom half of states on most dimensions. Among the states in the bottom quartile overall (Mississippi, Alabama, West Virginia, Oklahoma, Indiana, Kentucky, Tennessee, Florida, Louisiana, Georgia, New York, and Nevada), many are in the South, and have among the lowest median incomes and highest rates of both poverty and disability in the nation. This pattern largely holds across all dimensions. Among southern states, only Virginia and North Carolina rank in the top half overall. See Exhibit 3 for the geographic pattern of overall LTSS system performance.

Exhibit 2

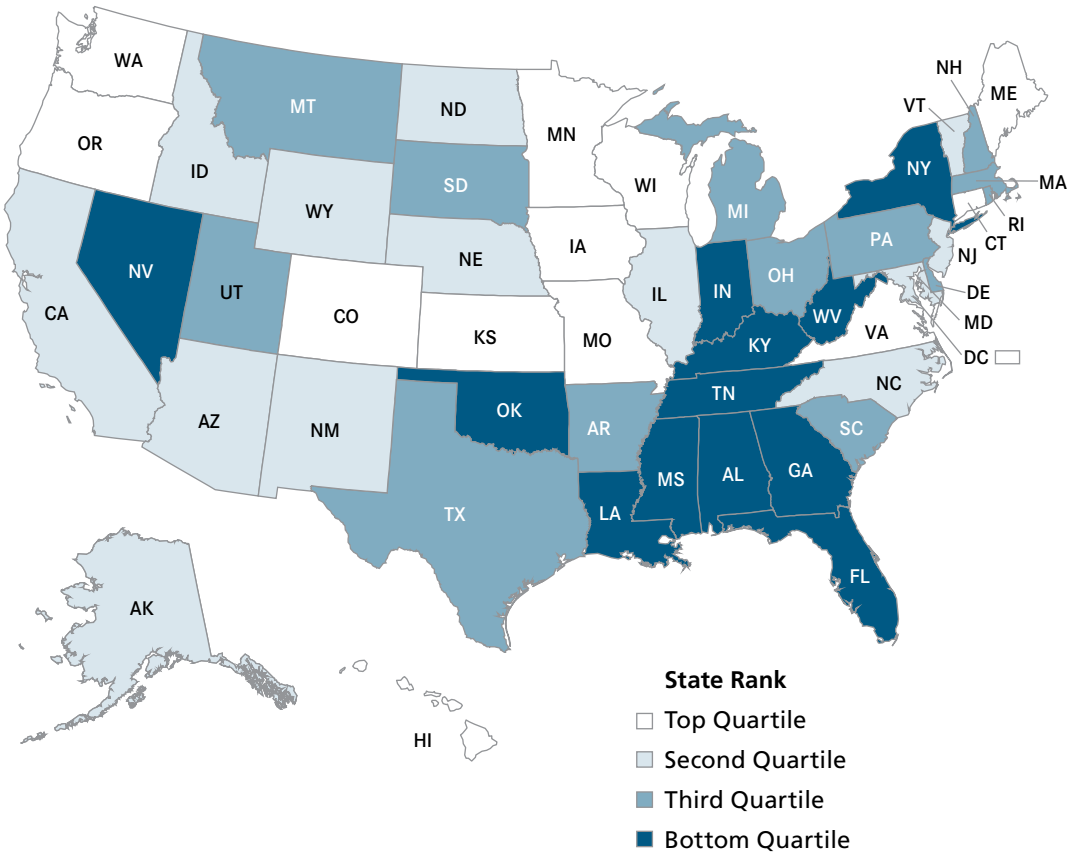
List of 25 Indicators in State Scorecard on Long-Term Services and Supports System Performance

	Dimension and Indicator	Year	All States Median	Range of State Performance (bottom–top)	Top State
	Affordability and Access				
1	Median annual nursing home private pay cost as a percentage of median household income age 65+	2010	224%	444%–166%	DC, UT
2	Median annual home care private pay cost as a percentage of median household income age 65+	2010	89%	125%–55%	DC
3	Private long-term care insurance policies in effect per 1,000 population age 40+	2009	41	28–300	ME
4	Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance	2008–09	49.9%	38.7%–63.6%	ME
5	Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community	2007	36.1	15.9–74.6	MN
6	ADRC/Single Entry Point functionality (composite indicator, scale 0–12)[a]	2010	7.7	1.0–11.0	MN
	Choice of Setting and Provider				
7	Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities	2009	29.7%	10.5%–63.9%	NM
8	Percent of new Medicaid LTSS users first receiving services in the community	2007	49.9%	21.8%–83.3%	MN
9	Number of people consumer-directing services per 1,000 adults age 18+ with disabilities	2010	8.0	0.02–142.7	CA
10	Tools and programs to facilitate consumer choice (composite indicator, scale 0–4)[a]	2010	2.75	0.50–4.00	IL, PA
11	Home health and personal care aides per 1,000 population age 65+	2009	34	13–108	MN
12	Assisted living and residential care units per 1,000 population age 65+	2010	29	7–80	MN
13	Percent of nursing home residents with low care needs	2007	11.9%	25.1%–1.3%	ME
	Quality of Life and Quality of Care				
14	Percent of adults age 18+ with disabilities in the community usually or always getting needed support	2009	68.5%	61.3%–78.2%	AK
15	Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life	2009	85.0%	80.2%–92.4%	SD
16	Rate of employment for adults with ADL disability ages 18–64 relative to rate of employment for adults without ADL disability ages 18–64	2008–09	24.2%	17.6%–56.6%	ND
17	Percent of high-risk nursing home residents with pressure sores	2008	11.1%	17.2%–6.6%	MN
18	Percent of long-stay nursing home residents who were physically restrained	2008	3.3%	7.9%–0.9%	KS
19	Nursing home staffing turnover: ratio of employee terminations to the average number of active employees	2008	46.9%	76.9%–18.7%	CT
20	Percent of long-stay nursing home residents with a hospital admission	2008	18.9%	32.5%–8.3%	MN
21	Percent of home health episodes of care in which interventions to prevent pressure sores were included in the plan of care for at-risk patients	2010	90%	77%–97%	HI
22	Percent of home health patients with a hospital admission	2008	29.0%	40.2%–21.8%	UT
	Support for Family Caregivers				
23	Percent of caregivers usually or always getting needed support	2009	78.2%	71.0%–84.0%	OR
24	Legal and system supports for caregivers (composite indicator, scale 0–12)[a]	2008–10	3.17	0.50–6.43	OR
25	Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks)	2011	7.5	0–16	CO, IA, MO, NE, OR

[a] Composite indicators combine information on multiple policies and programs; see Appendix B2 for detail.
Notes: See Appendix B2 for data year, source and definition of each indicator. ADL = Activities of Daily Living; ADRC = Aging and Disability Resource Center; HCBS = Home and Community-Based Services.
Source: State Long-Term Services and Supports Scorecard, 2011.

Exhibit 3

State Ranking on Overall LTSS System Performance



Source: State Long-Term Services and Supports Scorecard, 2011.

Many states have opportunities to improve

States that ranked in the second quartile (Nebraska, Arizona, California, Alaska, North Dakota, Idaho, Vermont, Wyoming, New Jersey, Illinois, Maryland, North Carolina, and New Mexico) all scored in the top quartile on at least one dimension. With the exception of Alaska (an unusual state because of its unique geography), no state in the second quartile scored in the bottom quartile on more than one dimension. These states all have areas of success, and can also improve to a higher level of performance by targeting their efforts in areas where they lag, and where other states have shown the path to higher performance.

Wide variation exists within dimensions and indicators

Wide variation exists within all dimensions, with low-performing states being markedly different from those that score high. In many cases, low-performing states have not adopted public policies that increase access to services or that enable consumers to exercise choice and control. Substantial variations also are found in the quality of service delivery and in measures of support for family caregivers.

State Medicaid policies dramatically affect consumer choice and affordability

Medicaid is the primary source of public funding for LTSS. It plays a leading role in determining the extent to which low-income older people, people with disabilities, and their families receive support through home- and community-based services (HCBS). It also affects the extent to which people with LTSS needs who want to avoid entering nursing homes are able to do so, by facilitating or hindering the choice of alternative settings, such as assisted living and supportive services in the home.

This is an area over which states have direct control, and some states have led the way to improve access and choice in Medicaid. These policy decisions are reflected in the proportion of Medicaid LTSS spending that states devote to HCBS and their success in supporting new program participants' choice of HCBS, as opposed to nursing homes.

Support for family caregivers goes hand in hand with other dimensions of high performance

The *Scorecard* reports on assistance for family caregivers by assessing whether they are receiving needed support and by examining state laws that can aid caregivers. But the most meaningful support for caregivers is a better overall system that makes LTSS more affordable, accessible, and higher quality, with more choices. Thus, high state scores on access, affordability, and choice may reflect states' recognition that caregivers are essential and policies that aid them include building a strong overall system. Very few states that score highly on support for family caregivers score poorly on other dimensions, and few states that score poorly on the caregiving dimension are ranked in the top quartile overall.

States can improve their performance by exceeding the federal requirements for the Family and Medical Leave Act and mandating paid sick leave to help working family caregivers, as well as preventing impoverishment of the spouses of Medicaid beneficiaries who receive HCBS. States also can implement programs to assess the needs of family caregivers and provide respite care and other services to help support their ongoing efforts.

Better data are needed to assess state LTSS system performance

At this time, limited data make it difficult to fully measure key concerns of the public and of policymakers, including the availability of housing with services, accessible transportation, funding of respite care for family caregivers, and community integration of people with disabilities. Improving consistent, state-level data collection is essential to evaluating state LTSS system performance more comprehensively. Most critically, an important characteristic of a high-performing LTSS system identified by the *Scorecard* team—how well states ensure effective transitions between hospitals, nursing homes, and home care settings and how well LTSS are coordinated with primary care, acute care, and social services—cannot be adequately measured with currently available data.

It is our hope that improved data collection will enable future *Scorecards* to expand upon the strong set of foundational indicators in this initial *State LTSS Scorecard* and provide a more complete and comprehensive analysis of LTSS system performance in the future.

The cost of LTSS is unaffordable for middle-income families

The cost of services, especially in nursing homes, is not "affordable" in any state. The national average cost of nursing home care is 241 percent of the average annual household income of older adults. Even in the five most affordable states, the cost averages 171 percent of income, and in the least affordable states it averages an astonishing 374 percent. When the cost of care exceeds median income to such a great degree, many people with LTSS needs will exhaust their life savings and eventually turn to the public safety net for assistance.

Though less extreme, the cost of home health care services also is unaffordable for the typical user, averaging 88 percent of household income for older adults nationally. People who receive home care services must add these costs to all their other living expenses. If they cannot afford the home care services they need, they may place added burdens on family caregivers who most likely already are providing services.

Impact of Improved Performance

States can improve their LTSS system performance in numerous ways. Improvement to levels achieved by top-performing states would make a difference to the 11 million older people and adults with physical disabilities who have LTSS needs,[2] and their family caregivers, in terms of access, choice, and quality of care. For example:

- If all states' public safety nets were as effective as that of Maine in covering low-income people with disabilities, an additional 667,171 individuals would receive coverage through Medicaid or other public programs. Such coverage would link people with disabilities and limited incomes to health care as well as long-term services and supports.
- States that effectively inform people with LTSS needs about home and community care options and offer an array of service choices can address the preferences of consumers in a cost-effective manner. If all states rose to Minnesota's level of performance on this measure, 201,531 people could avoid costly and unnecessary nursing home use.
- Many nursing home residents with low care needs can be, and would prefer to be, served in the community. If all states achieved the rate found in Maine, 163,441 nursing home residents with low care needs would instead be able to receive LTSS in the community.
- Excessive transitions between care settings such as nursing homes and hospitals reflect poor coordination of services and are correlated with poor quality of care. If all states matched the performance of Minnesota, 120,602 hospitalizations could be avoided, saving an estimated $1.3 billion in health care costs.

Key Findings on Select Indicators and Public Policy Actions to Improve Performance

The *Scorecard* is a tool to help states improve their LTSS systems. The key findings that follow illustrate areas in which there is a large range in state performance and examples of how public policy action can lead to improvement.

Medicaid safety net

The *Scorecard* finds great variation in the percentage of the low- and moderate-income population with a disability in activities of daily living (ADLs) that is covered by the Medicaid LTSS safety net. In a typical month, the top five states provide Medicaid LTSS to 63 percent of this population. By contrast, in the bottom five states, coverage averages just 20 percent—less than a third of the rate in the top states. The national average is 37 percent.

Policy action: States have substantial control over establishing financial eligibility standards for Medicaid coverage. States also have great flexibility to determine the level of disability needed to qualify for services.

LTSS "balancing"

The five highest performing states on the proportion of Medicaid and state general revenue LTSS spending for older people and adults with physical disabilities going toward HCBS spend, on average, 60 percent of their dollars on HCBS. The average proportion of spending across the United States is 37 percent, and the five lowest performing states devote just 13 percent of Medicaid LTSS spending (for older people and adults with physical disabilities) to HCBS. Relatively few states "balance" spending, that is, spend more than half of their LTSS dollars for HCBS. *The extent of such balancing in the top states is nearly five times as high as in the bottom states.*

Policy action: This is an area over which state governments have tremendous control and, through their public policies, can make considerable strides in ensuring that people who need LTSS can choose noninstitutional options for care. States that have improved the balance of services away from institutions and toward HCBS have taken advantage of Medicaid "optional" services such as HCBS "waivers" and the Personal Care Services option. States also can pursue new opportunities offered by the *Patient Protection and Affordable Care Act* to improve the balance of their LTSS systems.

Maximizing consumer choice of LTSS options

The *Scorecard* finds a threefold difference between the five top- and bottom-performing states in the percentage of new Medicaid beneficiaries who receive HCBS before receiving any nursing home services. This indicator measures the LTSS system's ability to serve people in the community rather than a nursing home when they need support. In the top five states, on average, 77 percent of new Medicaid LTSS beneficiaries receive HCBS. By contrast, in the bottom five states, only 26 percent of new LTSS beneficiaries receive HCBS. The average across all states is 57 percent. Failing to serve new beneficiaries in HCBS settings can have negative impacts for an extended duration: those who enter a nursing home have a more difficult time returning to the community, even if they can and want to live in the community.

Policy action: State policies such as "options counseling" and nursing home diversion programs can help to direct new LTSS users

toward HCBS rather than nursing homes. States also can implement "presumptive eligibility" procedures to quickly establish that a person will be able to qualify for public support for HCBS, thereby preventing unnecessary nursing home admissions.

Consumer direction

The *Scorecard* finds wide variation in the extent to which state systems allow program participants to direct their own services. Variously referred to as consumer direction, participant direction, or self-direction, this model allows the individual to hire and fire a worker he or she chooses, set the hours for service delivery, and, in some cases, determine the wages paid.[3] Over the past several decades, self-direction has proven to be increasingly popular with many participants. The *Scorecard* finds that California was the highest ranking state, reporting 143 people receiving self-directed services per 1,000 adults with disabilities, or about 1 in 7. The average in the next four top-performing states was 51 people per 1,000 adults with disabilities. The national average was 22 people per 1,000 adults with disabilities. In each of the six lowest performing states, fewer than 1 out of every 1,000 adults with disabilities received self-directed services.

Policy action: States have great flexibility to give people who use LTSS the option to direct their own services in publicly funded programs. These programs often allow participants to have greater flexibility as to when services are delivered and who provides them. Such programs also can expand the available workforce, as many participants choose to hire family members who would not otherwise be working in this field.

Nursing home residents with low care needs

The *Scorecard* finds a tremendous range in the percentage of nursing home residents with low care needs. Because the national trend is that people with low care needs receive services in the community, states with a relatively high proportion of nursing home residents with low care needs may be offering an inadequate array of alternatives to nursing homes. In the five top-performing states, only 5 percent of long-stay nursing home residents had low care needs. By contrast, in the bottom five states, the proportion of nursing home residents with low care needs averaged 22 percent; more than four times the rate in the highest performing states.

Policy action: Taking advantage of federal grants such as Money Follows the Person can help states to move nursing home residents who want to return to the community into their own homes or apartments.

Pressure sores among nursing home residents

A key indicator of LTSS quality is the percentage of high-risk nursing home residents who develop pressure sores, a condition that is preventable with good-quality care. The *Scorecard* finds that the bottom five states have more than twice the level of long-stay nursing home residents with pressure sores, compared with the top five states: 16 percent compared with 7 percent.

Policy action: States have the responsibility to establish and enforce high standards for providers and effectively monitor the quality of care nursing homes provide. Every state is funded to operate a nursing home ombudsman program, but each state can determine how frequently the ombudsmen visit each facility, how they respond to complaints, and the

methods they use to monitor quality. State nursing home inspectors have a major role in enforcing federal directives to reduce pressure sores, and states can use quality bonuses to reward providers who demonstrate significant progress.

Preventing hospitalizations

Another indicator of LTSS quality, both in nursing homes and among home health patients, is the rate of hospitalizations. People who are receiving appropriate primary care and whose medical care is well coordinated with other services and supports should have fewer hospitalizations. States that do a better job of monitoring the quality of nursing home and home health care will reduce unnecessary hospital stays and, thus, achieve lower costs. The *Scorecard* finds that the bottom-performing states had, on average, three times the rate of hospitalization of long-stay nursing home residents compared with the top states: 29 percent compared with 10 percent.

Better quality of care can be cost-effective as well. For example, there is a strong correlation between occurrence of pressure sores and hospital admissions among long-stay nursing home residents (see Exhibit 15, p. 48). This finding is important for two reasons. Pressure sores are preventable with high quality of care and can result in serious, life-threatening infections in people who develop them. In addition, transitions between settings (e.g., nursing home to hospital), especially those that are caused by poor quality care, are both costly and often traumatic for LTSS users and their family caregivers. Though the variation is less dramatic, hospitalization rates among home health patients in the bottom five states averaged 37 percent, compared with 23 percent among the top five states.

Policy action: Some states are beginning to develop more coordinated service delivery systems that integrate primary, acute, chronic, and long-term services. Integrated approaches such as the Program of All-Inclusive Care for the Elderly (PACE) have a proven record of improving outcomes and reducing the use of institutions.

Nurse delegation

State Nurse Practice Acts usually determine the extent to which direct care workers can provide assistance with a broad range of health maintenance tasks.[4] For this *Scorecard*, we asked the National Council of State Boards of Nursing about state practices in delegating 16 specific tasks, including administration of various types of medications, ventilator care, and tube feedings. The five top-performing states allowed all 16 tasks to be delegated, whereas the bottom six states allowed none to be delegated. The median number of tasks that states allowed nurses to delegate was 7.5. Lower ranked states can learn from the top performers that delegation of these tasks to direct care workers is possible and supports consumers' choice to live in homelike settings.

Policy action: State policy directly determines what health-related tasks can be delegated. Unlike some policy changes that may cost states money and are therefore more challenging to implement, changing nurse practice laws will, if anything, save money in public programs by broadening the type of workers who can safely perform these tasks.

Conclusion

The *Scorecard* finds wide variation across all dimensions of state LTSS system performance. Part of this variation is attributable to the fact that the United States does not have a single unified approach to the provision of LTSS. The primary public program that funds LTSS is Medicaid: a federal-state partnership that gives states substantial flexibility to determine who is eligible for LTSS, how LTSS are accessed, what services will be provided, what the payment rates will be, and where services will be delivered. This flexibility provides opportunities to learn from creative approaches to delivering services yet results in disparities in the support available to frail older people and low-income people with disabilities. But there is also a need to learn from successful states so that the health and independence of people who need LTSS are not at risk because of their state of residence.

The *Affordable Care Act* offers states promising new incentives for improving their LTSS systems, and the lowest performing states have the most to gain by taking advantage of these new provisions. Reforms offer the opportunity to raise the bar for all states, particularly states that are lagging behind, to achieve the vision stated in legal and public policy goals. The Supreme Court in the 1999 *Olmstead* decision affirmed the right of people with disabilities to live in the least restrictive environment appropriate to their needs.[5] States that provide limited HCBS options through their Medicaid programs, do not provide sufficient information about or facilitate access to HCBS options, do not offer enhanced support to family caregivers, or do not effectively use home care workers to perform health maintenance tasks can learn from leading states that doing so can be cost-effective as well as responsive to the needs and preferences of older adults and people with disabilities.

Geography should not determine whether people who need LTSS have a range of choices for affordable, high-quality services. All Americans should share a unified vision that supports the ability of older people to have choices, and to be able to age in their own homes with dignity and the support they need to maximize their independence. The lives of people with disabilities should be integrated into the community, where they can maintain social connections, engage productively through employment or other meaningful activities, and contribute to the rich diversity of American life.

Building an improved system is possible and must begin now: the successes achieved by leading states have already shown the way. It is time to raise expectations for LTSS performance. We must move to become a nation in which older people and those with disabilities are given meaningful choices, have access to affordable, coordinated services, a high quality of life and care, and support for their family caregivers regardless of the state they live in.

INTRODUCTION

In recent years, policymakers, providers, and advocates have grappled with the challenge to ensure that all Americans have access to high-quality, affordable health care. This critical debate often overshadows an equally compelling crisis: the unmet need for long-term services and supports (LTSS) that help older adults and people with disabilities to have a high quality of life and as much independence and control as possible.

The population is aging, disability among working-age adults has increased, and most states are in the midst of an economic downturn. These forces are creating a challenging environment for state policymakers, who have been working to improve their system of delivering the LTSS that older adults and people with disabilities need. A set of uniform, consistent benchmarks of state performance can help states identify where to focus their efforts and help them rise to the level of top-performing states.

The idea to create a *State LTSS Scorecard* emerged from previous scorecard efforts that have measured state performance specific to health. In 2006, The Commonwealth Fund published a *National Scorecard on U.S. Health System Performance*, followed, in 2007 and 2009, by a *State Scorecard on Health System Performance*. Those reports provided a framework for evaluating the core dimensions of a high-performing health care system. Expanding these efforts to long-term services and supports, the AARP Public Policy Institute, with the support of the AARP Foundation and its grantors, The Commonwealth Fund and The SCAN Foundation, has prepared this

WHAT ARE LONG-TERM SERVICES AND SUPPORTS?

Long-term services and supports (LTSS) may involve, but are distinct from, medical care for older people and adults with disabilities. Definitions of the term vary, so we must articulate what is meant. In this report, we define LTSS as follows:

Assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) provided to older people and other adults with disabilities who cannot perform these activities on their own due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically 90 days or more.

LTSS include human assistance, supervision, cueing and standby assistance, assistive technologies/devices and environmental modifications, health maintenance tasks (e.g., medication management), information, and care and service coordination for people who live in their own home, a residential setting, or a nursing facility. LTSS also include supports provided to family members and other unpaid caregivers.

Individuals with LTSS needs may also have chronic conditions that require health/medical services. In a high-performing system, LTSS are coordinated with housing, transportation, and health/medical services, especially during periods of transition among acute, post-acute, and other settings.

For the purpose of this project, people whose need for LTSS arises from intellectual disabilities (ID) or chronic mental illness (CMI) are not included in our assessment of state performance. The LTSS needs of these populations are substantively different than the LTSS needs of older people and adults with physical disabilities. Including services specific to the ID and CMI populations would have required substantial additional data collection, which was beyond the scope of this project. This LTSS definition was developed with input from a National Advisory Panel and a Technical Assistance Panel (referred to as the Scorecard Advisors). See Appendix B1 for more information about the process.

Scorecard to assess the overall performance of LTSS systems in every state and across key dimensions.

The purpose of this report, oriented toward state policymakers, state and national leaders, and other key stakeholders, is to inform efforts to improve state performance so that residents of all states are able to easily access an affordable range of high-quality LTSS. Such a system would help people with disabilities to exercise choice and control over their lives, thereby maximizing their independence and well-being. It also is critical that states act to support the family caregivers who undergird the entire system.

This *Scorecard* is intended to be a tool that policymakers and other stakeholders can use to identify areas where improvement is needed, provide a baseline against which to measure efforts to improve performance, uncover gaps within the system, and highlight the need for better information across a broader range of services. In all cases, we used the most recently available data for each indicator. It is possible that states have made changes to their LTSS systems in the interim – both improvements, as well as cuts. For this reason, successive *Scorecards* will be a useful tool to measure state progress over time.

We recognize that state policymakers' degree of control over the indicators varies. State policymakers have direct control over several indicators, and they can influence other indicators through oversight activities and incentives. Other indicators are more influenced by policies and practices in the private sector. Our intention is that this *Scorecard* will begin a dialogue among key stakeholders to explore LTSS performance and facilitate actions that will result in progress across dimensions. Furthermore, we hope that the *Scorecard* will underscore the need for states to develop better measures of performance over a much broader range of services and collect data in order to more comprehensively assess the adequacy of their LTSS systems.

The *Scorecard* is timely and relevant, given the recent enactment of the *Patient Protection and Affordable Care Act* of 2010. The *Affordable Care Act* offers states helpful new options and enhanced federal funding to create a care system that embodies many aspects of a high-performing system, as outlined here.[6] In particular, the *Affordable Care Act* gives states opportunities to make Medicaid more responsive to the preferences of people with disabilities by enhancing the funding of home- and community-based services (HCBS) and improving the coordination of services.

The ultimate goal of a high-performing LTSS system should be to enhance the well-being and quality of life of individuals who are at risk because of chronic conditions, illness, injury, or other causes of disability. It also should help to maintain their families in their role as caregivers. A "high-performing" or excellent system is marked by five key characteristics:

1. Affordability and access: consumers can easily find and afford the services they need, and there is a safety net for those who cannot afford services.
2. Choice of setting and provider: a person-centered approach to LTSS places high value on allowing consumers to exercise choice and control over where they receive services and who provides them.
3. Quality of life and quality of care: services maximize positive outcomes,

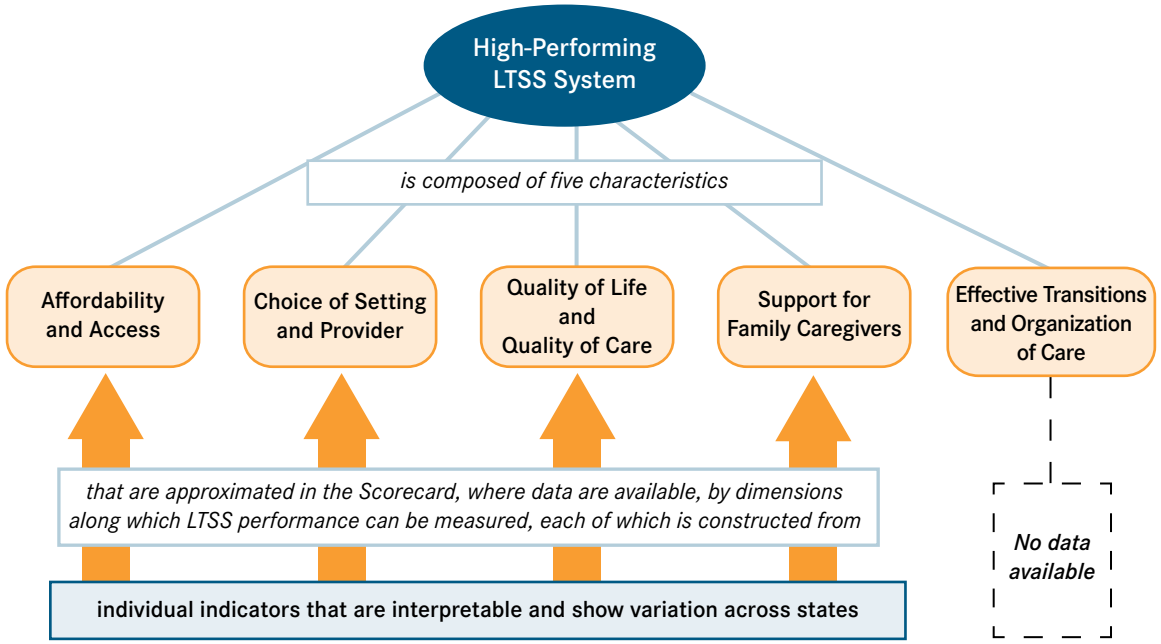
and consumers are treated with respect. Personal preferences are honored when possible.

4. Support for family caregivers: the needs of family caregivers are assessed and addressed so that they can continue in their caregiving role without being overburdened.
5. Effective transitions and organization of care: LTSS are effectively coordinated or integrated with health-related services, as well as with social supports.

The characteristics of a high-performing LTSS system were developed in consultation with the *Scorecard* Advisors and recently articulated by the authors in *Health Affairs*.[7] (See Appendix B1 for more information about the process.) These characteristics are aims—goals to strive for when considering public policies and private sector actions that affect the organization, delivery, and financing of LTSS. Exhibit 4 illustrates how the elements of a high-performing LTSS system are represented in the *Scorecard* by four dimensions, each comprised of three to nine data indicators. Adequate data to assess states' performance on effective transitions and organization of care were not available, despite being identified by the *Scorecard* team as an important characteristic of a high-performing LTSS system. After extensive attempts to identify consistent state-level data to measure performance, we determined that assessing states in this area would remain a goal for the future. Thus, the *Scorecard* focuses on four rather than five dimensions.

Exhibit 4

Framework for Assessing LTSS System Performance



Source: State Long-Term Services and Supports Scorecard, 2011.

The *Scorecard* includes 25 indicators, grouped into the four dimensions: (1) affordability and access, (2) choice of setting and provider, (3) quality of life and quality of care, and (4) support for family caregivers. Each of these dimensions is composed of several indicators of state performance, selected with the assistance of the Scorecard Advisors. Decisions were influenced by the availability of clear, unambiguous, important, and meaningful indicators based on data that were available at the state level. (See Appendix B1 for more information on indicator selection.) While some of the indicators rely on data that have been reported elsewhere, many represent new measures. Several indicators are constructed from a range of data in a related area, facilitating the ability to rank states in areas of performance that are difficult to assess.

This *Scorecard* is the first of its kind: a multidimensional approach to measure state LTSS system performance overall and across diverse areas of performance. As such, the findings differ from analyses that examine a single aspect of states' LTSS systems, such as the "balance" of public services provided in home- and community-based settings compared with nursing homes. This multidimensional analysis involves a richer exploration of data to assess performance. Performance on some indicators is driven by actions of state policymakers, while rankings on other indicators are more likely to reflect actions by providers, families, or consumers. We sought to develop a tool that would be helpful in evaluating state LTSS performance. While we were challenged by the paucity of data in certain areas, we believe this *Scorecard* represents a good "starter set" of indicators for measuring state performance and a solid baseline for tracking progress over time.

The leading states indicate *what has already been achieved* and, therefore, set a standard by which other states can evaluate their performance at the present time. This does not indicate an upper limit, as even high-performing states can aspire to continued improvement. Nor do the rankings establish an absolute measure of the strength of the state LTSS systems: rather, they compare the states with each other using consistent data. All 50 states and the District of Columbia are ranked on each of the four performance dimensions and, except in a few instances in which data were not reported, they are ranked on each indicator, as well (see "A Note on Methodology" box).

Summary exhibits show each of the indicators, the range of variation across states, overall state rankings, and ranks within each dimension. Exhibit 5 presents the overall rankings and where each state ranks in each of the four dimensions.

In the sections that follow, we present the *Scorecard* results, organized by the four dimensions of performance, as well as sections that describe major findings, the role of public policies and the private sector, the impact of improved performance, the need for improvement, and conclusions. Appendices at the end of the report contain data for all states and indicators, organized by dimension. State data on demographics, income, poverty status, and disability are included, and may help the reader frame the social and economic context in which each state is operating. All data are available at www.longtermscorecard.org.

A NOTE ON METHODOLOGY

Dimensions and Indicators: The *Scorecard* measures LTSS system performance using 25 indicators, grouped into four dimensions:

Affordability and Access includes the relative affordability of private-pay LTSS, the proportion of individuals with private long-term care insurance, the reach of the Medicaid safety net and the Medicaid LTSS safety net to people with disabilities who have modest incomes, and the ease of navigating the LTSS system.

Choice of Setting and Provider includes the balance between institutional services and HCBS, the extent of participant direction, and the facilitation of consumer choice in publicly funded LTSS programs. It also measures the supply and availability of alternatives to nursing homes.

Quality of Life and Quality of Care includes level of support, life satisfaction, and employment of people with disabilities living in the community, and indicators of quality in nursing homes and in home health services.

Support for Family Caregivers includes level of support reported by caregivers, legal and system supports provided by the states, and the extent to which registered nurses are able to delegate health maintenance tasks to nonfamily members, which can significantly ease burdens on family caregivers.

For each of the four dimensions, the *Scorecard* uses specific indicators that are important, meaningful, conceptually valid, and unambiguous in regard to directionality; these are combined to obtain state rankings at the dimension level. In some cases, composite indicators have been formed from thematically related program and policy data. Indicators are based on data that are expected to be updated regularly so that change can be observed over time. (See Exhibit 2 in the executive summary for a complete list of the indicators.) Appendix B2 describes the methodology for the development of each composite indicator.

The four measured dimensions of system performance approximately correspond to four of the five key characteristics of a high-performing LTSS system (see Exhibit 4). However, the correspondence is not complete, as data are not currently available to measure important aspects of some of the characteristics. Notable data gaps include coordination of LTSS with other services (medical, housing, transportation, and more), consumer reports of quality of HCBS, and consistent definition and measurement of respite for family caregivers.

All indicators are subject to definitional and measurement issues; these 25 were selected because they represented the best available measures at the state level. While no single indicator may fully capture state performance, taken together they provide a useful measure of how state LTSS systems compare across a range of important dimensions.

Ranking Methodology: The *Scorecard* ranks the states from highest to lowest performance on each of the 25 indicators. We averaged rankings for those indicators within each of the four dimensions to determine each state's dimension rank, and then averaged the dimension rankings to arrive at an overall ranking. This approach gives each dimension equal weight in the overall rankings, and within dimensions gives equal weight to each indicator. In the case of missing data or ties in rank for an indicator, minor adjustments were made to values used in the average so that all indicators were given equal weight.

- For ties: the average rank is given for the computation of the dimension or overall average (e.g., two states tied at third; both get a score of 3.5 for the calculation of the dimension average).
- Missing data: a constant value is added to all ranks so that the average rank for the indicator is 26 (e.g., if there were 4 missing values, the scores would run from 3 to 49 instead of 1 to 47 for the calculation of the dimension average).

This approach was chosen for ease of understanding and interpreting the results, and for consistency with the 2007 and 2009 *State Scorecards on Health System Performance*.

Exhibit 5

State Ranking on LTSS System Performance by Dimension

(1) = State in top quartile

Overall Rank*	State	Affordability & Access Rank	Choice of Setting and Provider Rank	Quality of Life & Quality of Care Rank	Support for Family Caregivers Rank
50	Alabama	46	50	35	50
17	Alaska	43	(1)	(1)	41
15	Arizona	39	18	26	(3)
37	Arkansas	32	26	41	22
15	California	(7)	(9)	39	30
(7)	Colorado	20	(10)	19	(6)
(11)	Connecticut	(8)	25	17	20
32	Delaware	27	49	(7)	28
(10)	District of Columbia	(1)	24	27	14
44	Florida	35	37	44	41
42	Georgia	33	44	31	24
(4)	Hawaii	14	20	(3)	(10)
19	Idaho	48	(8)	23	(12)
23	Illinois	(12)	33	24	27
47	Indiana	49	39	43	43
(6)	Iowa	22	22	(5)	(5)
(9)	Kansas	(9)	23	14	17
46	Kentucky	51	43	50	24
43	Louisiana	18	46	46	36
(8)	Maine	24	(13)	(12)	(11)
24	Maryland	(3)	28	33	34
30	Massachusetts	17	14	34	39
31	Michigan	37	15	21	33
(1)	Minnesota	(4)	(3)	(4)	(4)
51	Mississippi	49	51	51	36
(13)	Missouri	(5)	31	32	(9)
33	Montana	36	21	(10)	47
14	Nebraska	29	36	(6)	(13)
40	Nevada	43	38	38	(8)
27	New Hampshire	22	29	20	28
22	New Jersey	(10)	34	28	21
26	New Mexico	(13)	(5)	35	45
41	New York	25	17	39	48
24	North Carolina	(11)	(7)	45	35
18	North Dakota	29	41	(2)	16
35	Ohio	34	26	37	23
48	Oklahoma	37	42	49	51
(3)	Oregon	26	(5)	(13)	(1)
39	Pennsylvania	47	(12)	22	46
34	Rhode Island	41	32	15	30
38	South Carolina	15	35	29	44
29	South Dakota	28	48	(11)	14
45	Tennessee	42	47	48	26
28	Texas	20	19	42	19
36	Utah	45	30	(8)	38
20	Vermont	19	(4)	30	39
(12)	Virginia	(2)	16	25	32
(2)	Washington	(6)	(2)	18	(2)
49	West Virginia	40	45	46	49
(5)	Wisconsin	16	(11)	(9)	17
20	Wyoming	29	40	15	(7)

*Final rank for overall LTSS system performance across four dimensions.
Source: State Long-Term Services and Supports Scorecard, 2011.

SCORECARD FINDINGS BY DIMENSION

Dimension 1: Affordability and Access

LTSS needs commonly arise from disabling chronic conditions, such as multiple sclerosis, Parkinson's disease, or Alzheimer's disease. But very often, the need for LTSS arises suddenly as the result of an accident or acute health crisis, such as a broken hip or a stroke. After acute medical needs are met, there may be an immediate and continuing need for LTSS. Individuals and families may be confronted by a complex and confusing set of decisions. They often have to act quickly, with varying amounts of information or help. Once they manage to find the services needed, they often are shocked by the high cost. The median national cost of a private room in a nursing home was about $75,190 per year in 2010, and even a semiprivate (shared) room cost $67,525. Prices vary widely and can easily exceed $100,000 per year in high-cost markets. Typical assisted living costs were $38,220 per year. The median hourly cost of home care was $19. Thus, the cost of using 30 hours per week of services, a typical amount, comes to $29,640 per year.[8] The cost of LTSS can be a threat not only to individuals' independence and financial security, but also that of their families. As illustrated by *Scorecard* affordability indicators, in all states the annual costs of nursing home care exceed median incomes.

Such services and care typically are not covered by either private health insurance or Medicare. The bulk of publicly financed LTSS is provided under need-based state programs (mainly Medicaid), for which there is great variation in the types of services available and the criteria used to determine eligibility.[9] Even greater variation is seen in each state's decision about the scope of services that will be authorized for eligible individuals and the settings in which they may be received.

In a high-performing system, individuals and their families can easily navigate their state's LTSS system, finding readily available, timely, and clear information to make decisions about LTSS. Services are affordable for those with moderate and higher incomes, and a safety net is available for those who cannot afford services, with eligibility determined easily and quickly and low rates of impoverishment caused by use of LTSS.

The *Scorecard* includes six indicators that measure the affordability and accessibility of LTSS in a state:

- The private pay cost of nursing homes as a proportion of household income for people age 65 or older;
- The private pay cost of home health services as a proportion of household income for people age 65 or older;
- The rate of private long-term care insurance policies in effect among people age 40 or older;
- The percentage of adults with ADL disability and limited income who receive Medicaid;
- The percentage of adults with ADL disability and limited income who receive Medicaid LTSS; and
- A composite indicator that measures the level of functionality of a state's system for accessing LTSS through a single entry point.

Appendix B2 presents full descriptions and definitions of each indicator.

The first three indicators measure affordability and access across a range of the income spectrum. Few Americans, even those with incomes well above the level that would qualify them for need-based programs, can afford to pay out-of-pocket for LTSS over a long period. Private long-term care insurance provides a way for people with moderate or higher incomes to increase access to services when they need them, while protecting their savings and other assets. In addition, those who have private long-term care insurance generally can afford to obtain more services than those who must pay out-of-pocket.

Among those with low or modest incomes, virtually no amount of LTSS is affordable out-of-pocket. For these individuals, a robust safety net—typically provided by Medicaid and other

MEDICAID

Medicaid is a federal-state program that provides health care and LTSS to people with low incomes and few assets. The federal share, referred to as the federal medical assistance percentage (FMAP), is based on the state's median income. It ranges from 50 percent in wealthier states to 75 percent in the poorest state.[10] In 2009, Medicaid LTSS (including nursing home and HCBS) spending totaled $119 billion, which is about one-third of all Medicaid spending.[11] Within broad federal rules, states have considerable flexibility in determining who may qualify for Medicaid and what services they will receive. To qualify for LTSS, individuals must meet three major criteria:

Income: A state may use numerous income eligibility pathways. In nearly all states, individuals may qualify for Medicaid if they have incomes that do not exceed the federal Supplemental Security Income (SSI) level ($674 per month for a single person in 2011, $1,011 for a couple). Several states have extended eligibility up to 100 percent of the federal poverty level (about $908 per month for a single person in 2011, $1,133 for a couple). About two-thirds of the states allow people with LTSS needs to have income up to 300 percent of SSI. States also vary in the extent to which they allow beneficiaries with higher incomes to qualify after "spending down" their incomes paying for health and LTSS costs. For example, Medicaid beneficiaries in nursing homes generally must contribute all their income (except for a small "personal needs allowance"—usually $30 to $50 per month) to pay for the services they receive, and Medicaid pays the remainder of the cost. Married beneficiaries also may protect some income to support a spouse who lives in the community.

Assets: In most states, an individual may not have more than $2,000 in assets to qualify for Medicaid, although the home is generally considered an exempt asset. Many people enter a nursing home paying for services out-of-pocket. After exhausting their life savings, they may qualify for Medicaid. Married beneficiaries also may protect some assets for a community-residing spouse.

Functional Criteria: In order to qualify for LTSS, an individual must meet the state's "level of care" (LOC) criteria. Each state develops its own standards. In some states, LOC is based primarily on limitations in ADLs or measures of cognitive impairment. In other states, specific medical criteria must be met. While it is difficult to compare states' LOC criteria, it may be harder for low- or modest-income people with LTSS needs to qualify for services in states that use medical criteria than in states that use only ADL criteria.

state-funded programs—is important to ensure access to services. In addition, because the cost of LTSS is so high, many individuals even with significant assets may exhaust their life savings paying for services and then turn to Medicaid as their last resort.

The *Scorecard* also measures access through a composite indicator that measures the level of functionality of a state's system for accessing LTSS through Aging and Disability Resource Centers (ADRCs) or other entities that help consumers learn about LTSS and how they might get the services they need. Known in the field as "a single entry point" or a "no wrong door" approach, the goal is to help people navigate the complex world of LTSS so they can more easily access services that meet their needs and preferences.

The *Scorecard* finds that the top-performing states on this dimension are the District of Columbia, Virginia, Maryland, Minnesota, and Missouri (see Appendix A2). Notably, Washington, DC, and its surrounding states (Maryland and Virginia) top the dimension ranking. One reason this region scores high on affordability may be that median income in the DC metropolitan area is extremely high, yet the cost of services, especially in outlying parts of the surrounding states, is only slightly above the national average. Yet the cost of services, especially in nursing homes, cannot be called "affordable" in any state, as average costs greatly exceed median income for the at-risk population. Moreover, even though services may be comparatively more affordable in some states, people with lower incomes will find it difficult to pay for services, even in the most "affordable" states.

This dimension includes a diverse set of indicators, and the *Scorecard* does not find uniform performance across the indicators. Most states scored high in some areas and low in others. A substitution effect may be at work, since the less affordable private pay LTSS becomes, the greater role long-term care insurance and the public safety net must play in ensuring access to services. There is some evidence that this is indeed happening: each measure of private pay affordability has a weak to moderate negative correlation with each measure of the reach of the Medicaid safety net.

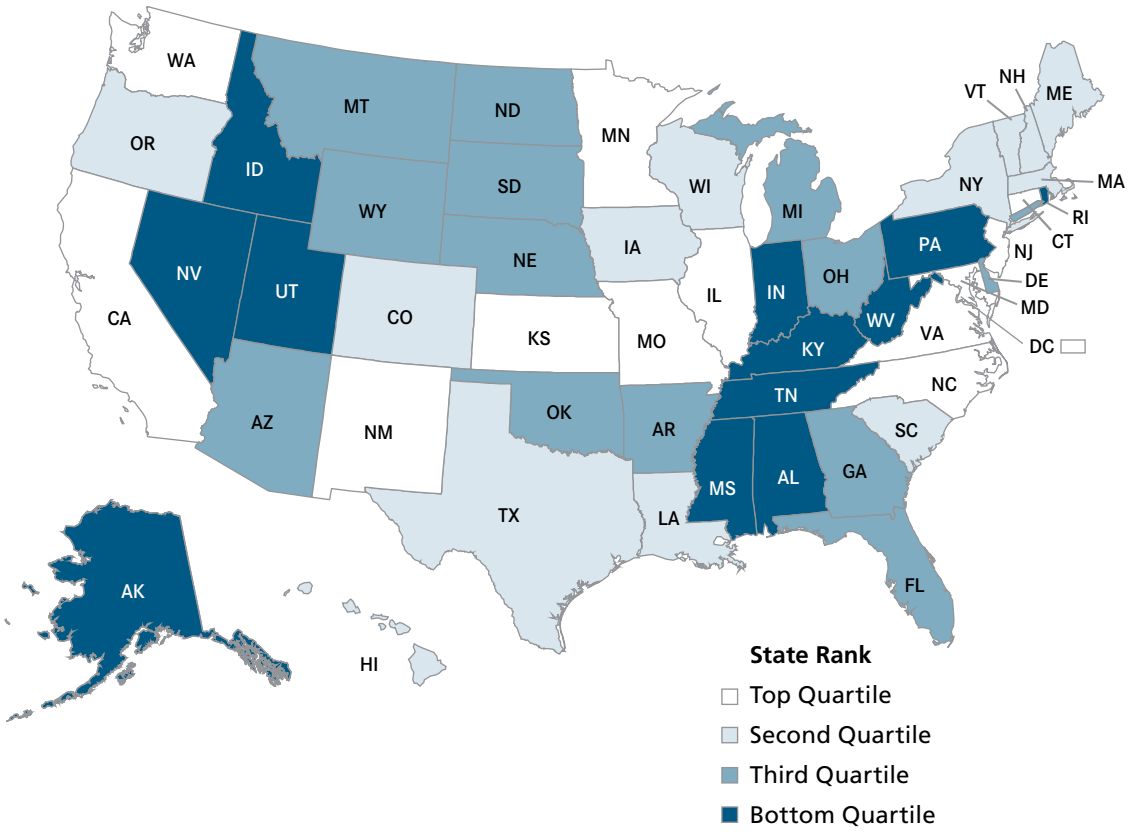
Every state in the top quartile for this dimension (see Exhibit 6 for states' rankings by quartile) was in the bottom half of states for at least one indicator; similarly, each state in the bottom quartile overall was in the top half of states for at least one indicator. This finding indicates that even high-performing states have gaps in access or affordability, and all states have strengths that they can build upon in this area.

Private Pay Affordability

Most people express a preference for receiving services in their own homes or in homelike settings that enable independence with support. People generally fear both the high cost and the loss of autonomy associated with an extended nursing home stay. Yet regardless of the setting, the cost of paying for LTSS can overwhelm a family's finances.

Two indicators measure the median private pay cost of a private room in a nursing home and the median private pay cost of 30 hours per week of a licensed home health aide as a proportion of the median household income for people age 65 or older (the population most

State Ranking on Affordability and Access Dimension



Source: State Long-Term Services and Supports Scorecard, 2011.

likely to need LTSS). Among people with ADL disabilities who use paid home care services, 30 hours per week is a typical level of use.[12] There may be considerable variation in LTSS costs and incomes within as well as between states (see Exhibit 7); the median cost-to-income ratio is calculated at the market level and then averaged across all markets in the state.[13] Results are reported as the percentage of cost compared to income. Thus, a lower percentage indicates greater affordability. In a less affordable state, these costs might wipe out all savings and qualify a person for Medicaid nursing home services, at significant cost to the state. When services are more affordable, individuals with LTSS needs also have more control over the type of services they receive.

Nursing Home Costs

In the five most affordable states for nursing home care (District of Columbia, Utah, Missouri, Kansas, and Iowa), the annual nursing home cost averages 171 percent of older people's annual household income. This rate contrasts sharply with the five least affordable states, where the average nursing home cost to income ratio is 374 percent—more than twice the level in the most affordable states. The national average is 241 percent. When the cost of care exceeds median income to such a degree, many people with LTSS needs will ultimately exhaust their life

savings and eventually turn to the public safety net for assistance.

Overall, no relationship was seen between the state-level median income of households age 65 or older and private pay nursing home affordability (see Exhibit 8). For example, some low-income states such as Louisiana are more affordable because the cost of nursing homes is relatively low, even though incomes are also low. Other states, such as Maryland, are relatively affordable because incomes are more robust and the cost of care is comparatively moderate. Connecticut is an example of a high-income state that is not affordable because of very high nursing home costs.

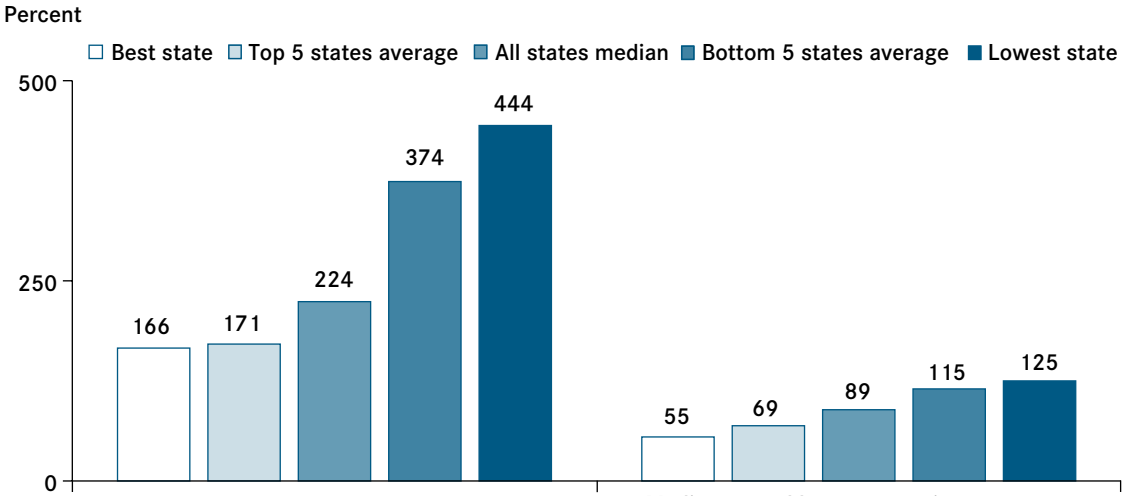
Home Health Costs

The *Scorecard* also finds substantial variation in the affordability of home health care services. The private pay cost of home care services averaged 69 percent of household income in the five most affordable states (District of Columbia, Maryland, Virginia, Hawaii, and Wyoming). By contrast, in the five least affordable states, home care costs averaged 115 percent of household income—about two-thirds higher than in the most affordable states. The national average was 88 percent.

People who receive home care services must add these costs to all their other living expenses. If they need substantial paid home

AFFORDABILITY AND ACCESS Exhibit 7

State Variation: Private Pay Nursing Home and Home Health Cost



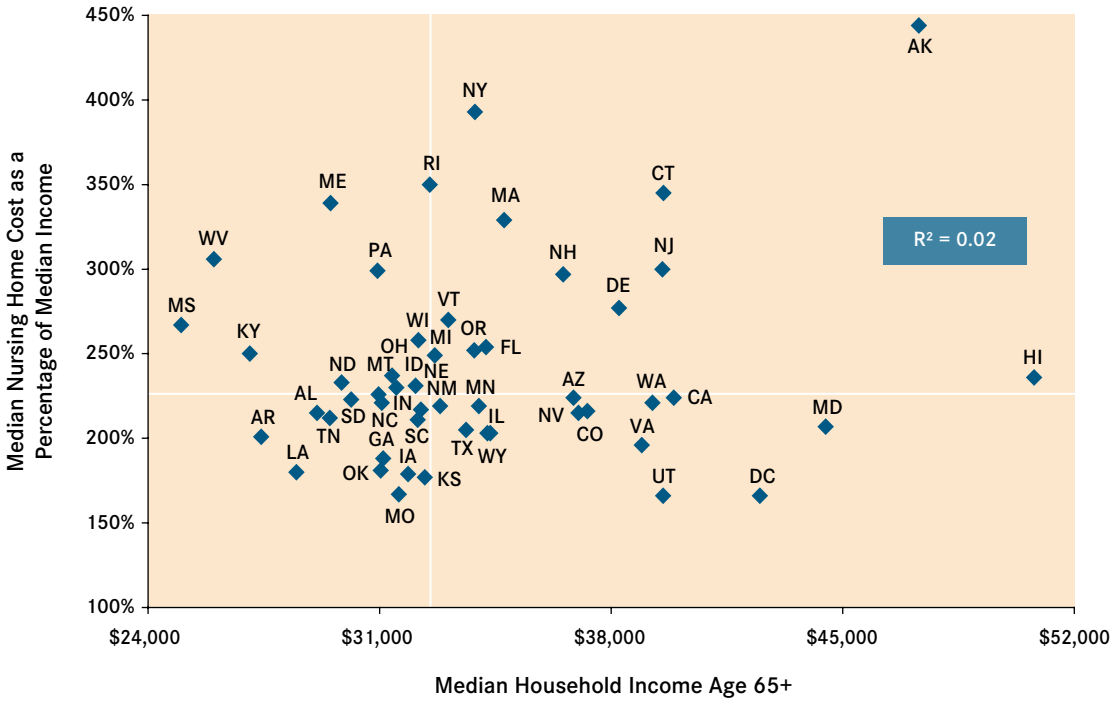
Top 5 states

Nursing home	Home care
1. District of Columbia	1. District of Columbia
1. Utah	2. Maryland
3. Missouri	2. Virginia
4. Kansas	4. Hawaii
5. Iowa	5. Wyoming

Data: AARP Public Policy Institute analysis of 2010 Genworth Cost of Care Survey and 2009 American Community Survey Public Use Microdata Sample.
Source: State Long-Term Services and Supports Scorecard, 2011.

AFFORDABILITY AND ACCESS Exhibit 8

Private Pay Nursing Home Cost and State Median Income Age 65+



Data: Data: AARP Public Policy Institute analysis of 2010 Genworth Cost of Care Survey and 2009 American Community Survey Public Use Microdata Sample.
Source: State Long-Term Services and Supports Scorecard, 2011.

care services, they may find themselves unable to continue paying their utility, insurance, food, and other bills. As is the case with the affordability of nursing home services, people who cannot afford the home care services they need may ultimately turn to Medicaid or other public programs for help. If these programs have not invested adequately in HCBS, they may offer limited alternatives to entering a nursing home. Moreover, people who cannot afford the home care services they need may place added burdens on family caregivers, who most likely already are providing services.

Unlike with nursing homes, there is a relationship between state income and home health affordability on a private pay basis.

Private Long-Term Care Insurance

Estimates of the number of Americans covered by private long-term care insurance (LTCI) range from about 6 million[14] to 8 million.[15] According to the American Association for Long-Term Care Insurance, claims were paid to nearly 135,000 individuals in an average month in 2010. Thirty-eight percent of new claims paid for nursing home services. Thirty-one percent of claims paid for home care and 31 percent for assisted living services.[16] Thus, the number of people in a state who have private LTCI is a useful indicator of access to services of all types. A higher number indicates greater coverage and thus, higher performance.

This indicator measures the number of policies in effect per 1,000 people age 40 or older. In 2009, people age 40 or older purchased 94 percent of policies sold in the individual insurance market and 75 percent of policies in the group market.[17] Those with private insurance may have access to services they could not otherwise afford or that is not available through the publicly funded safety net, such as additional home care to supplement a family caregiver or to pay for assisted living. For example, Medicaid and state general revenue programs pay for services for only about 12 to 15 percent of assisted living residents.[18]

The *Scorecard* finds tremendous variation in the rate of private LTCI coverage across the states. In Maine, there were 300 policies in effect per 1,000 people age 40 or older, almost two and one-half times the rate of coverage in the next highest state. More than in other states, a large proportion of the policies sold in Maine are group policies, which usually are offered by employers. Nearly 90 percent of Maine's long-term care insurance policies in effect are from the group market. Group policies often are less expensive than individual policies, in part because of lower administrative and marketing costs, but also because purchasers tend to be younger.[19] Nationally, almost two-thirds of LTCI policies are from the individual market. The coverage rate in the next four states (Hawaii, District of Columbia, South Dakota, and North Dakota) is 113 policies per 1,000. This level of penetration is almost four times that found in the bottom states (29 policies per 1,000 people age 40 or older). The national average is just 44 policies per 1,000 people age 40 or older.

The Publicly Funded Safety Net

Medicaid is the primary source of funding for LTSS.[20] Disability rates are highest among those with low incomes,[21] and even people with moderate incomes can become impoverished by high medical and LTSS expenses. Although broad federal rules govern the program, each state has extensive flexibility with regard to eligibility and services provided by the Medicaid safety net, including both the level of income and assets a beneficiary may retain and still qualify for either nursing home or HCBS coverage.[22] Two indicators measuring the percentage of adults with ADL disability and limited income who receive Medicaid, or who participate in and receive Medicaid LTSS, are used to describe the reach of the safety net.

Low-Income Adults with Disabilities Receiving Medicaid

A critical measure of access is how restrictive the state's Medicaid financial eligibility criteria are for people with disabilities. This indicator estimates Medicaid participation by adults with ADL disability who have incomes at or below 250 percent of the poverty threshold (about $27,900 per year for a single person under age 65, about $25,700 for a single person age 65 or older).[23] Establishing the income eligibility for Medicaid in every state is a complex process. This indicator measures the percentage of people with ADL disability age 21 or older with low or modest incomes who are covered by Medicaid or other publicly funded health insurance.

A higher percentage of people with disabilities and modest incomes who receive Medicaid or other need-based public health

insurance indicates a more effective Medicaid safety net. Individuals in these states are more likely to receive the services they need. The *Scorecard* finds that Medicaid coverage in the top five states (Maine, New York, Massachusetts, Alaska, and District of Columbia) is 62 percent of the low- and moderate-income at-risk population, compared with just 41 percent in the bottom five states.

Low-Income Adults with Disabilities Receiving Medicaid LTSS

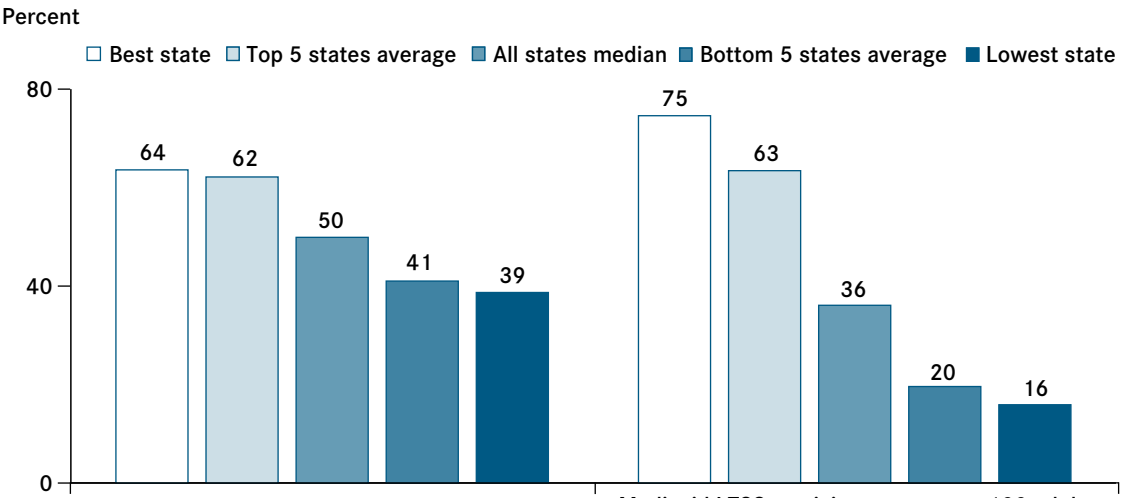
The previous indicator measured the likelihood that adults with LTSS needs and low or modest incomes would qualify for Medicaid. This indicator examines the likelihood of such individuals actually receiving Medicaid LTSS. Receipt of LTSS may be affected by the state's functional eligibility criteria (see Medicaid box on page 26), as well as waiting lists for HCBS waiver services. In a state with restrictive functional eligibility criteria, someone might qualify for Medicaid but not be able to obtain LTSS. Much of the difference in relative rank in the two safety net indicators can be explained by relatively broad or narrow functional eligibility criteria. In a state with limited HCBS, some people with LTSS needs forego receiving services rather than enter a nursing home.

This indicator measures the number of Medicaid LTSS participant-years per 100 people age 21 or older with ADL disability and income

AFFORDABILITY AND ACCESS

Exhibit 9

State Variation: Reach of Medicaid Safety Net



Top 5 states

1. Maine	1. Minnesota
2. New York	2. California
3. Massachusetts	3. Vermont
4. Alaska	4. Connecticut
5. District of Columbia	5. Washington

Note: ADL = Activities of Daily Living.
Data: Data: Percentage on Medicaid– AARP Public Policy Institute analysis of 2009 American Community Survey Public Use Microdata Sample. Percentage on Medicaid LTSS–Mathematica Policy Research analysis of 2006/2007 Medicaid Analytical Extract (MAX); AARP Public Policy Institute analysis of 2007 American Community Survey Public Use Microdata Sample [note, removed ;] and AARP Public Policy Institute, *Across the States 2009: Profiles of Long-Term Care and Independent Living*.
Source: State Long-Term Services and Supports Scorecard, 2011.

at or below 250 percent of poverty. This can be thought of as the percentage of the state's adult population with ADL disability and low or modest incomes who receive Medicaid LTSS in a typical month. A higher percentage indicates a more effective Medicaid LTSS safety net.

This indicator does *not* indicate the robustness of the services provided by the state. A state may have more restrictive financial or functional eligibility standards but offer a very rich package of LTSS to the smaller number of people who qualify. Another state may have looser financial or functional eligibility criteria but offer very limited services to those who qualify.

The *Scorecard* finds great variation in the percentage of the low- and moderate-income at-risk population that is covered by the Medicaid LTSS safety net; the variation between states in percentage of the at-risk population actually receiving services is much wider than variation in Medicaid coverage (see Exhibit 9). In a typical month, the top five states (Minnesota, California, Vermont, Connecticut, and Washington) provide Medicaid LTSS to 63 percent of the at-risk population. By contrast, in the bottom five states, coverage averages just 20 percent—less than a third of the rate in the top states. The national average is 37 percent.

ADRC/Single Entry Point Functionality

Navigating a state's LTSS system can be a daunting task. When a sudden need for LTSS arises, families may be confronted by a complex and confusing set of decisions to make, without knowledge of what options are available: types of services, public programs that may offer assistance, and more. Even among people who have the resources to pay out-of-pocket for services, it can be confusing and time-consuming to find a reliable provider. The Centers for Medicare & Medicaid Services (CMS) and the Administration on Aging have awarded grants to states to develop Aging and Disability Resource Centers (ADRCs).[24] The ADRCs are charged with being "one-stop shops" that can serve people of all incomes and types of disability—directing them to available resources in their community based on their care needs and eligibility. While not all states have fully functioning, statewide ADRCs, some operate other "single entry points" that perform some or all of the functions of an ADRC. Other states are less developed in facilitating access to services and information.

This indicator measures state performance in 12 functions typically provided by ADRCs and other single entry points. Among the functions assessed were the following:

- Populations served
- Assistance with information about and referral to services
- Options counseling (to inform people of alternatives to nursing homes)
- Financial eligibility determination
- Level of care/functional eligibility determination

In constructing this indicator, the *Scorecard* team relied on two primary sources of information. Data collected for AoA by The Lewin Group were used to assess a wide range of functions performed by ADRCs. An AARP survey supplemented this information by collecting data on the functions performed by other entities that offer single entry point or no

wrong door help to consumers to sort through what they need and want, and where they can get it. Approximately two-thirds of the indicator is ADRC functionality, and the other one-third represents functions provided by a single entry point of any type. Each function was scored between 0 and 1, ranging from inadequate or not available to fully functioning. The maximum score for a state with a fully functioning access system is 12. Appendix A5 presents all composite scores, as well scores for each function.

The *Scorecard* found that states spanned practically the entire spectrum from inadequate to fully functioning, from a low of 1 point to a high of 11 points (Minnesota). Facilitating ease of access to LTSS is a critical state function and indicates a state's commitment to helping people with disabilities find and access the most appropriate services and supports to meet their needs.

While many states have received federal grants to establish or expand their ADRC system, receipt of a federal grant is not sufficient to ensure a highly functioning system. Rather, it takes a combination of political will, organizational structure, and coordinated effort to establish an effective system. To succeed, states must make it a policy priority to facilitate consumer access to information and services. Some leading states such as Oregon and Washington established single point of entry systems years ago, long before the concept of the ADRC was developed. This is an area in which the top-performing states could provide useful lessons to help lower performing states improve their access systems. In addition, a new round of federal grants to states to adopt or expand ADRCs is expected to result in measurable progress in future *Scorecards*.

Dimension 2: Choice of Setting and Provider

At every stage of life, people value and need choices and autonomy over decision making. Because individuals with LTSS needs must rely on others to help them perform basic tasks of everyday living, it is especially important that they be able to have choices and exert control over decisions affecting their LTSS arrangements. A lack of choice over what types of services and supports are received, who provides them, and in what setting they are received leads to a profound loss of independence. Inability to exercise choice and control can be frustrating, and is exacerbated by an LTSS system limited in service options because of lack of information, inadequate supply of providers, and lack of choices in public programs.

Because individual LTSS needs are unique, a high-performing system will offer a rich array and adequate supply of service options, provided in a range of housing alternatives. Services must have the flexibility to meet individual needs and preferences. Few states have a shortage of supply/capacity for nursing facility services, but many states have a dearth of home- and community-based alternatives, or do not make these alternatives to institutional care equally available through public programs.[25] Only a handful of states spend more than half of their Medicaid LTSS dollars for older people and adults with physical disabilities on services in home- and community-based settings, which consumers overwhelmingly prefer.[26] There is limited public coverage for care in individuals' homes, assisted living, small group homes in residential neighborhoods, adult day services,

and enriched housing environments in most states.[27]

In a high-performing LTSS system, a "person-centered" approach allows people with LTSS needs to receive services in the setting of their choice from providers they choose, regardless of source of payment. While public programs must balance the cost and availability of service options, consumer preferences should be an important component of decision making. A range of housing choices supports the ability of people with LTSS needs to maintain vital connections to their community. Consumers are involved in decision making about care arrangements, and self-direction is an option. Clients may hire family members, neighbors, and friends as caregivers if they choose to do so. There also is an adequate supply of direct care workers and alternative residential settings to nursing homes.

The *Scorecard* includes seven indicators that measure choice of setting and provider:

- The proportion of Medicaid LTSS spending that pays for HCBS;
- The proportion of new Medicaid LTSS beneficiaries who receive HCBS;
- The percentage of HCBS users in publicly funded programs who direct their own services;
- A composite indicator that assesses the degree of choice in public programs;
- The number of home care aides per the population age 65 or older;
- The number of assisted living and other residential care units, such as adult foster care, per 1,000 population age 65 or older; and
- The proportion of long-stay nursing home residents who have low care needs.

The first four indicators measure choice in public programs. Because Medicaid remains the primary payer for LTSS, each state's proportion of spending and new users who receive HCBS are two important areas to measure. Assessing the number of individuals in publicly funded HCBS programs who self-direct their services is another important component of choice. Variously called consumer direction, self-direction, or participant direction, this model allows individuals with disabilities to hire, manage, and fire direct care workers.[28] In some cases the participant has control over wages, services delivered, and the schedule for delivering services. Some programs convert the consumers' care plans to a pool of funds available to purchase goods and services that support their independence.

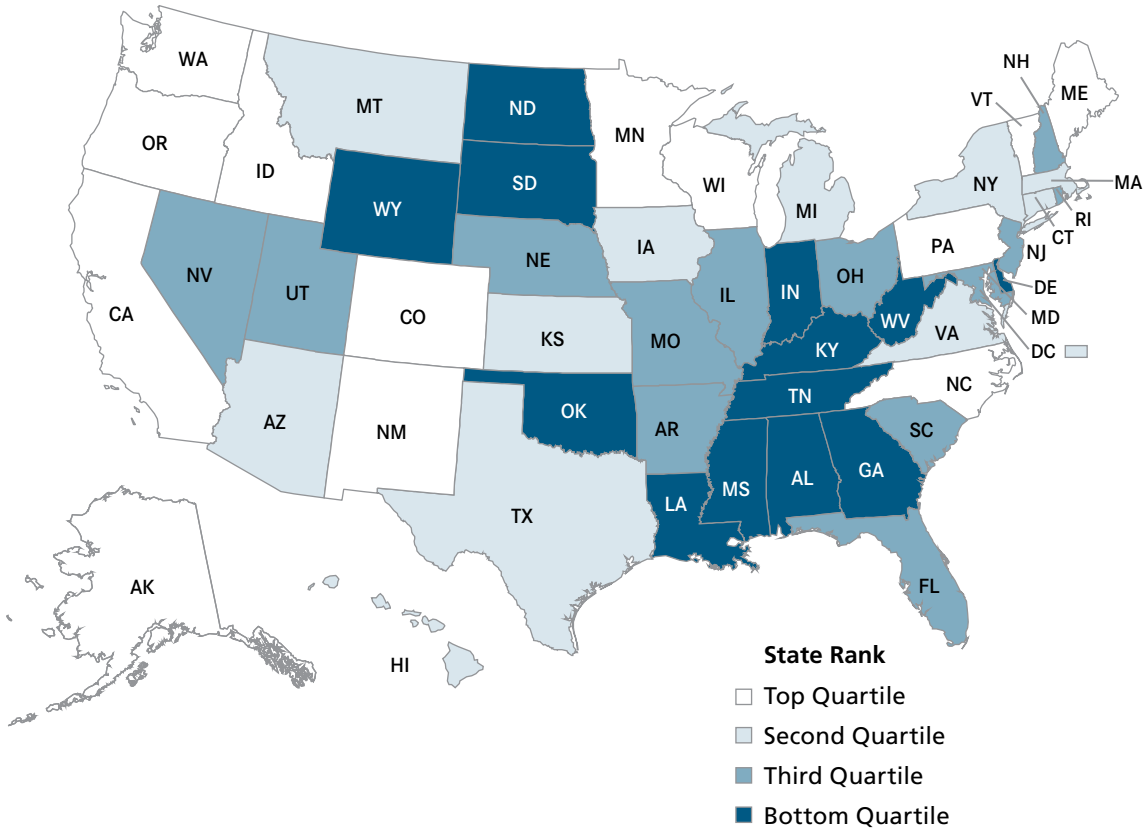
Most consumers hope to avoid entering a nursing home, but state programs do not always facilitate the choice to receive services at home or in homelike environments such as assisted living. The Medicaid program is structured such that people who meet the state's eligibility criteria are entitled to receive nursing home services, but states offer HCBS alternatives at their option. This has been referred to as an "institutional bias" in the Medicaid program. Consumers may not be aware of their full range of options, or may be steered into nursing homes because of barriers.

Workforce shortages also can constrain choice. The Bureau of Labor Statistics lists both home health aides and personal and home care aides among the top five fastest growing occupations from 2008 to 2018. The number

CHOICE

Exhibit 10

State Ranking on Choice of Setting and Provider Dimension



Source: State Long-Term Services and Supports Scorecard, 2011.

of home health aides is expected to increase by 50 percent in this period and the number of personal and home care aides by 46 percent.[29] Still, the Institute of Medicine identified the shortage of direct care workers as reaching a "crisis," especially in home care settings, as the demand for home care services grows.[30] Thus, the number of these aides per 1,000 population age 65 or older is a measure of a state's capacity to offer an adequate choice of providers.

The *Scorecard* finds that the five highest performing states for this dimension are Alaska, Washington, Minnesota, Vermont, and New Mexico (see Appendix A6). The leaders in this dimension ranked solidly highest in their ability to use Medicaid to serve people in HCBS. With only two exceptions (District of Columbia and Texas), every state that scored in the top quartile on these two indicators ended up among the top ten states for the entire dimension. (See Exhibit 10 for states' rankings by quartile.) Therefore, a state's commitment to "balancing" its Medicaid system may be a leading indicator for the entire choice dimension. Increasing balance in Medicaid-supported services may lay the groundwork for providers to invest in additional workers and HCBS infrastructure.

Balance in Medicaid and State-Funded LTSS

States vary widely in their progress away from a predominantly institutionally based Medicaid system and toward one that offers more HCBS choices (see Exhibit 11). This movement toward a better match between services offered and consumer preferences is often referred to as "balancing." In this analysis, we looked at states' spending on HCBS for older people and adults with physical disabilities, including both Medicaid and state-funded services. Because the *Scorecard* does not address the population with intellectual disabilities or chronic mental illness, only services used primarily by older people and adults with physical disabilities are included.

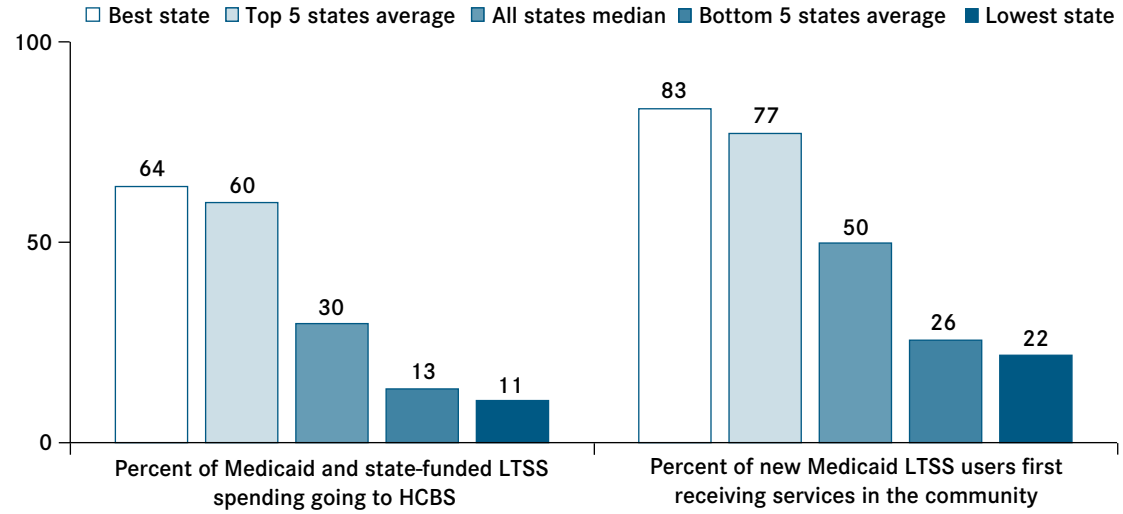
Percentage of Medicaid and State-Funded LTSS Spending Going to HCBS

Only a handful of states spend more than 50 percent of their Medicaid and state general revenue LTSS funds on HCBS for older people and adults with physical disabilities, and most states spend considerably less. In general, the balance of service provision toward HCBS is much greater for other LTSS populations, such as people with intellectual disabilities.[31] A higher percentage of HCBS indicates greater balance and, therefore, higher performance.

CHOICE

Exhibit 11

State Variation: Measures of Medicaid LTSS Balance



Top 5 states

Percent of Medicaid and state-funded LTSS spending going to HCBS	Percent of new Medicaid LTSS users first receiving services in the community
1. New Mexico	1. Minnesota
2. Washington	2. Michigan
3. Minnesota	3. Alaska
4. Oregon	4. New Mexico
5. Alaska	5. California

Note: HCBS = Home and Community-Based Services.
Data: LTSS Spending—AARP Public Policy Institute analysis of Thomson Reuters, Medicaid Long-Term Care Expenditures FY 2009; Thomson Reuters, Medicaid Managed Long-Term Services and Supports Expenditures (FY 2009); AARP Public Policy Institute *Weathering the Storm: The Impact of the Great Recession on Long-Term Services and Supports*; New Medicaid Users—Mathematica Policy Research analysis of 2006/2007 Medicaid Analytical Extract (MAX).
Source: State Long-Term Services and Supports Scorecard, 2011.

The five highest performing states are New Mexico, Washington, Minnesota, Oregon, and Alaska, which spend, on average, 60 percent of their Medicaid LTSS dollars (for older people and adults with physical disabilities) on HCBS. The average proportion of spending across the United States is 37 percent, and the five lowest performing states devote just 13 percent of Medicaid LTSS spending (for older people and adults with physical disabilities) to HCBS. *The extent of balancing in the top states is nearly five times as high as in the bottom states.* States have tremendous control over spending priorities and, through their public policies, can make considerable strides in establishing a public safety net that affords people who need LTSS choices besides nursing homes.

Percentage of New Medicaid LTSS Users First Receiving Services in the Community

This indicator measures whether a new Medicaid LTSS participant receives HCBS or is admitted to a nursing home. Because most people with LTSS needs would choose to remain in the community, receiving HCBS first is a direct measure of how well a state's system offers the choices that consumers want. HCBS can help people to remain in their homes longer; moreover, for those who enter a nursing home, it may be difficult or impossible to return to a home- or community-based setting. Therefore, this indicator assesses the share of *new* Medicaid LTSS participants who receive HCBS as opposed to nursing home services.

The *Scorecard* finds a nearly threefold difference between the five top- and bottom-performing states in their percentage of new Medicaid beneficiaries who receive HCBS before receiving any nursing home services. This indicator measures the LTSS system's ability to serve people in the community rather than a nursing home when the need for support arises. In the top five states (Minnesota, Michigan, Alaska, New Mexico, and California), on average, 77 percent of new Medicaid LTSS beneficiaries receive HCBS. By contrast, in the bottom five states, only 26 percent of new LTSS beneficiaries receive HCBS. The average across all states is 57 percent. Failing to serve new beneficiaries in HCBS settings can have negative impacts for an extended duration: those who enter a nursing home have a more difficult time returning to the community, even if they can and want to live in the community.

Consumer Direction

When Medicaid began to pay for HCBS as an alternative to nursing home care some 30 years ago, the traditional model was to authorize services provided through a home care agency. At the urging of adults with physical disabilities, a new model called consumer direction emerged. This model allows the individual to hire and fire a worker he or she chooses, set the hours for service delivery, and, in some cases, determine the wages paid.[32] Over the past several decades, self-direction has proven to be increasingly popular. It can help address workforce shortages, as many people choose to hire family members or other individuals they already know who would not otherwise be in this occupation.

This indicator measures the proportion of people with disabilities receiving consumer-directed services through a publicly funded program. Data were collected through a survey conducted by Penn State University for the National Resource Center for Participant-Directed Services at Boston College.[33] While

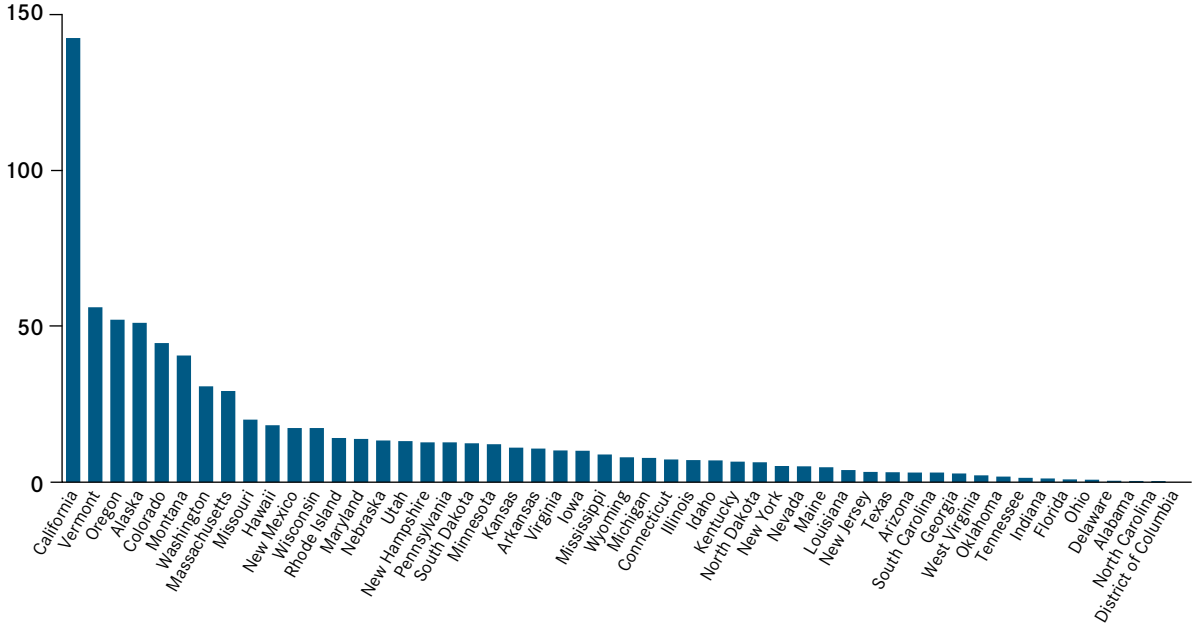
the programs and participants include all populations, some 84 percent of those served are older people and adults with physical disabilities, the target populations for this *Scorecard*. The number of people consumer-directing was divided by the population age 18 or older with any disability in the state. This group is much larger than the number with ADL disability.

The *Scorecard* finds that California was the highest ranking state, reporting 143 people receiving self-directed services per 1,000 adults with disabilities, or about 1 in 7 (see Exhibit 12). The average in the next four top-performing states (Vermont, Oregon, Alaska, and Colorado) was 51 people per 1,000 adults with disabilities. The national average was 22 people per 1,000 adults with disabilities. In each of the six lowest performing states, fewer than 1 out of every 1,000 adults with disabilities received self-directed services. Nearly two-thirds of all consumer-directing individuals in the country live in California. This finding is not surprising, given California's historic role in developing and supporting a consumer-directed approach to service delivery. In the 1960s, the independent living movement emerged in Berkeley, California, led by wheelchair-using adults who called for a greater role in determining the services and supports they needed to maximize their independence. California's In-Home Supportive Services program, started in the 1970s, was the nation's first and largest consumer-directed services program. Self-direction has continued to grow and is well established in the state.

CHOICE Exhibit 12

State Rates of Consumer Direction of Services for Adults with Disabilities

Number of people receiving consumer-directed services per 1,000 adults age 18+ with disabilities



Data: The SCAN Foundation, Financial Management Services in Participant Direction Programs, 2011; 2009 American Community Survey.
Source: State Long-Term Services and Supports Scorecard, 2011.

Facilitating Consumer Choice

The extent to which current policies facilitate choice of setting and provider varies widely across states. This composite indicator uses a broad range of functions to develop a single score for states' effectiveness in facilitating consumer choice to receive HCBS. It measures the degree to which states (a) facilitate timely access to HCBS by "presuming" Medicaid eligibility for individuals who are likely to qualify; (b) use standard uniform assessment tools to assess applicants for eligibility in Medicaid and state-funded LTSS programs; (c) provide options counseling to help consumers and their families make informed decisions about what LTSS options are available and which will best meet their needs and preferences; and (d) operate a nursing facility transition or Money Follows the Person program that offers nursing home residents an opportunity to move to the community, whether such programs operated statewide, and whether the program covers one-time transition services to help participants establish a community residence. Transition services are not typically covered by Medicaid, and may include paying the security deposit on an apartment or purchasing essential household furnishings and other items that are necessary for independent living.

The *Scorecard* finds, on a scale of 0 to 4—with scores of 0 to 1 on each of the four aspects of coordination—the top five states (Illinois, Pennsylvania, Washington, New Jersey, and New Hampshire) had an average score of 3.8, while the lowest five states averaged 0.8. The difference between the low- and high-performing states represents three of the four aspects of the indicator, going from "not at all" to "full performance." Appendix A7 presents all composite scores, as well scores for each function.

Home Health and Personal Care Aides

Frontline direct care workers are in significantly short supply in many communities.[34] As the population ages and states continue to progress toward greater LTSS balance, the shortage may become more acute. Whether one is paying a worker out-of-pocket, by private LTCI, or through a public program, an adequate supply of high-quality workers is necessary. Some states have expanded the workforce by allowing participants in public programs to hire family members, neighbors, and friends using public funds. This practice can help both people with LTSS needs and family caregivers who have reduced their hours or even left their jobs entirely to care for a family member.[35]

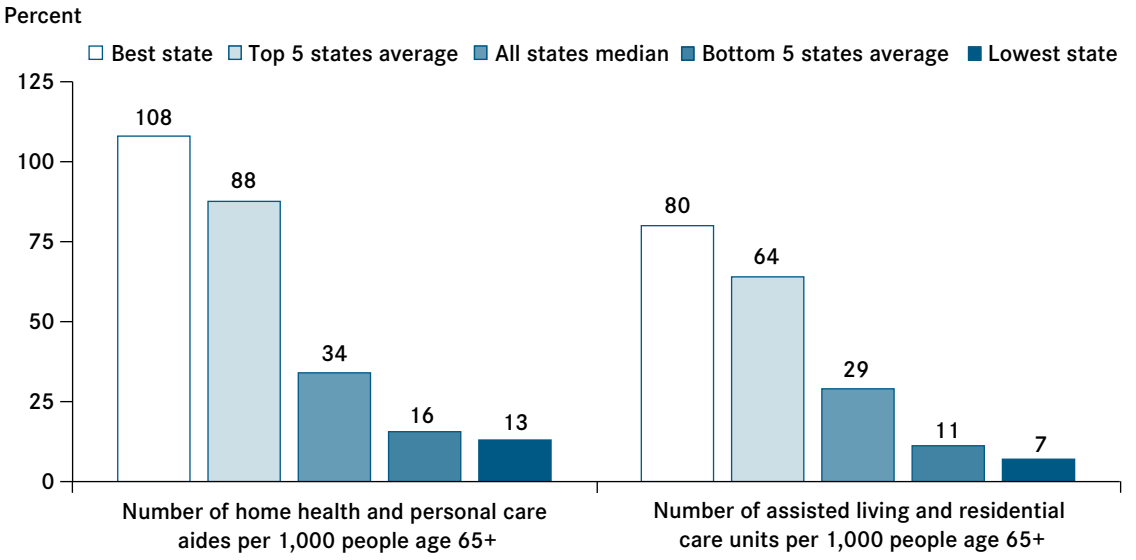
We use the number of personal, home care, and home health aides per 1,000 population age 65 or older as a measure of the availability of direct care workers in the community. Although this indicator can be influenced by a range of factors, including broader economic conditions and consumer-generated demand for HCBS, states can also have an impact on the availability of an adequate supply of workers through wage-setting practices, training opportunities, mechanisms to build career ladders, and policies that allow for payment of relatives.

The *Scorecard* finds that the availability of the LTSS workforce varies dramatically across the states (see Exhibit 13). In the five highest performing states (Minnesota, New York, New Mexico, Vermont, and North Carolina) there are, on average, 88 home health and personal care aides per 1,000 people age 65 or older. By contrast, there are, on average, only 16 home

CHOICE

Exhibit 13

State Variation: Home Health Aide and Assisted Living Supply



Top 5 states

1. Minnesota	1. Minnesota
2. New York	2. Oregon
3. New Mexico	3. Idaho
3. Vermont	4. Wisconsin
5. North Carolina	5. Alaska
	5. Washington

Data: Home Health Aide Supply—2009 Occupational Employment Statistics and 2009 U.S. Census Bureau population estimates; Assisted Living Supply—2010 AARP State LTSS Survey and 2009 U.S. Census Bureau population estimates.
Source: State Long-Term Services and Supports Scorecard, 2011.

care workers per 1,000 people age 65 or older in the five lowest performing states. The national average is 40 workers per 1,000 population age 65 or older.

Assisted Living and Residential Care

One factor in the declining use of nursing homes over the past two decades is the growth of residential alternatives such as assisted living and adult foster care.[36] While the majority of assisted living residents pay for services out-of-pocket, states can influence the availability of a range of assisted residential alternatives through their licensure laws and willingness to subsidize these alternatives for people who cannot afford the full cost. Only about 12 to 15 percent of assisted living residents have their services paid for by Medicaid and state-funded programs.[37] The availability of residential alternatives to nursing homes can be measured by the number of assisted living and residential care units per 1,000 people age 65 or older.

The *Scorecard* finds that there is an approximately sixfold difference between the average number of assisted living and residential care units per 1,000 persons age 65 or older in the top six states (Minnesota, Oregon, Idaho, Wisconsin, Alaska, and Washington) and the bottom five states (see Exhibit 13). The average in the top five states is 64 units per 1,000 people age 65 or older, compared with just 11 units per 1,000 people age 65 or older

in the bottom five states. The national average is 31 per 1,000. LTSS systems that have a large supply of affordable residential alternatives to nursing homes enable state residents to exercise desirable choices when they can no longer remain in their own homes, but still hope to avoid institutionalization.

A range of factors affect the supply of assisted living units, including historical, political, demographic, and cultural influences. In some states, policymakers have promoted home- and community-based services, including assisted living. In other states, political obstacles, including opposition from nursing home operators, have impeded the robust development of these alternatives. Some of the leading states—for example, Minnesota, Oregon, and Washington—have taken action to provide greater subsidies in assisted living for Medicaid beneficiaries or to promote small, family-like group home environments, sometimes called "adult foster care."[38] The numbers of older adults, the availability of capital, real estate values, and the age of the existing housing stock may also influence the supply.

Long-Stay Nursing Home Residents with Low Care Needs

Consumer preference for alternatives to nursing homes, such as assisted living or home care, is well documented, and national trends indicate that use of nursing homes is on the decline. Between 1984 and 2004, institutional use by older people declined by 37 percent.[39] As a result, people with a level of disability who would have been served in nursing homes in the past are now able to maintain a greater degree of independence by living in their own homes or alternatives such as assisted living. The number of community-residing older people with two or more ADL disabilities increased by two-thirds between 1984 and 2004.[40] The acuity level of nursing home residents is also on the rise. A higher percentage of nursing home residents who have low care needs may indicate that the state offers too few options to receive HCBS, or that these individuals entered a nursing home without knowing about available alternatives.

This indicator measures the percentage of nursing home residents who have low care needs, defined as residents who do not require physical assistance in any of the four late-loss ADLs (bed mobility, transferring, using the toilet, and eating) and are not classified in either the "Special Rehab" or "Clinically Complex" Resource Utilization Group (RUG-III).[41] A low percentage indicates high performance, as people with low care needs generally could be served outside of a nursing home.

The *Scorecard* finds a tremendous range on this indicator. In the five top-performing states (Maine, Hawaii, South Carolina, Pennsylvania, and Washington), only 5 percent of long-stay nursing home residents had low care needs. By contrast, in the bottom five states, the percentage of nursing home residents with low care needs averaged 22 percent: more than four times the rate in the highest performing states.

Given the role of Medicaid as the primary source of payment for nursing home services, states have substantial direct control over whether to serve people with LTSS needs in nursing homes or in the home and community settings that most people prefer; for those with low care needs, LTSS are likely to be lower cost as well. State progress in reducing unnecessary nursing home use would be both cost-effective and provide greater choice, control, and life satisfaction for people who need LTSS.

Under the Medicaid program, each state must establish what are called "level of care" criteria; that is, what level of health and functional disability must be demonstrated in order to be admitted to a nursing home. If a state's level of care criteria are minimal, people may be admitted to a nursing home who could be cared for in a less restrictive setting. One problem with the current system is that under the existing Medicaid HCBS "waiver" program (the primary way that people on Medicaid receive HCBS), beneficiaries can be served by the waiver only if they meet the state's nursing home care level criteria.

Some provisions of the *Affordable Care Act* begin to sever this link, allowing states to serve people with lower levels of disability in HCBS, reserving the more stringent criteria for nursing home coverage. Because each state's care level criteria are unique, it is difficult to determine whether these criteria are related to the number of people with low care needs in nursing homes. There appears to be some relationship, but it is not predictive.

Dimension 3: Quality of Life and Quality of Care

Quality in a high-performing LTSS system includes not only the quality of services received, but also the quality of life of people with LTSS needs. The delivery of LTSS should be free from abuse, neglect, and unsafe or unhealthy practices. While such problems are not the norm, the track record of LTSS providers is far from perfect.[42] In all settings, services and supports should be timely and appropriate to the individual, regulatory standards should be consistent with high quality and adequately enforced, providers should use evidence-based best practices, and clients should have good outcomes and be satisfied with the services they receive. In a high-performing system, the paid LTSS workforce is of sufficient size and adequately trained, job satisfaction is high, turnover is low, and payment rates are sufficient to support high-quality care.[43]

People who have LTSS needs often must navigate a complex system of service providers and settings, which may not communicate effectively with each other. Transitions between the home, the hospital, a rehabilitation facility, and a nursing facility are fraught with opportunities for breakdowns in the continuity of care. All too often, the result is mismanagement of medication regimes, inefficient delivery of services, and confusion for consumers and their caregivers. In a high-performing LTSS system, there is effective coordination or integration between health-related services (such as clinician services, medications, home health, and physical therapy) and supportive services (such as personal care, adult day, homemaker, transportation, and other services). When the broad range of services and supports is well coordinated, avoidable hospital admissions should be reduced.

Equally important is the quality of life that LTSS users experience. In addition to being safe and effective, LTSS in all settings should respect personal dignity and individual preferences, engage users with their community, and maintain or increase quality of life to the greatest extent possible.[44] For example, one individual might prefer to have a bath in the evening, whereas another might prefer to bathe in the morning. Whether an individual resides in a nursing home, an assisted living facility, or in her own home, she should be able to exercise

this control. Community engagement also is a critical component of life quality, regardless of where one lives. LTSS should prevent isolation, enable individuals to maintain contact with family and friends, and overcome barriers to full participation in the community, including social activities and employment opportunities. Thus, a high-performing LTSS system must attend to the social and emotional needs of consumers, and not just to their needs for help with their ADLs or health care.

The *Scorecard* includes nine indicators to measure this dimension, in three important areas of LTSS quality. Three indicators address the quality of life of people with disabilities living in the community:

- The percentage of people with disabilities who are getting needed support;
- The percentage of people with disabilities who are satisfied with life; and
- The percentage of working-age adults with disabilities who are employed.

Four indicators address quality of care in nursing homes:

- The percentage of nursing home residents who have pressure sores;
- The percentage of nursing home residents who are physically restrained;
- Nursing home staff turnover rates; and
- The percentage of long-stay nursing home residents who have a hospital admission.

The final two indicators address quality of care provided by home health agencies:

- The percentage of home health patients with a care plan to treat pressure sores; and
- The percentage of home health patients with a hospital admission.

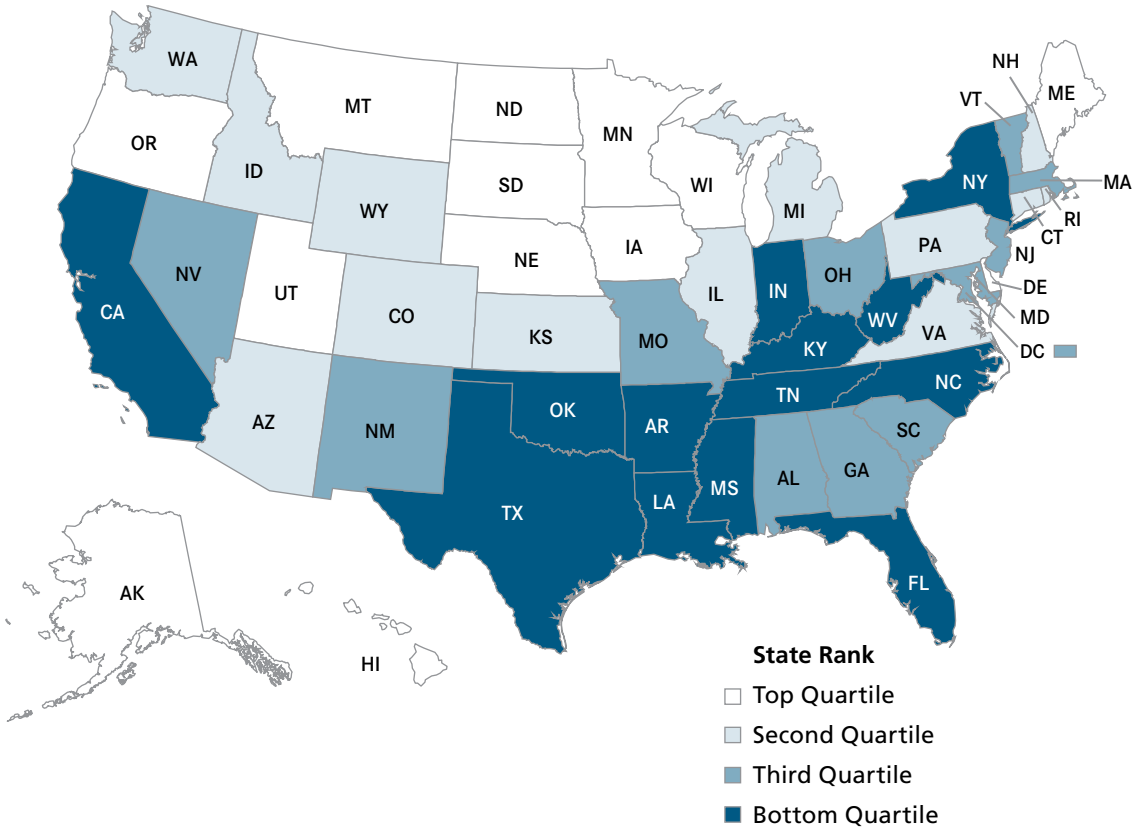
A fourth critically important aspect of LTSS quality cannot be included owing to lack of available data: quality of HCBS, including consumer and family experience with the full range of HCBS, such as adequacy of care plans, timely delivery of services, cultural competency, and other indicators. Few validated and reliable sources of data on HCBS quality are available, even at the individual state or national level, and none provides comparable data across states. Even within Medicaid, the largest source of public payment for HCBS, no measures of quality are uniformly applied across the states. Additional efforts to monitor HCBS quality are critical to quality assurance and improvement; data that can be used to compare outcomes across states, across programs, and across settings would be especially useful.

The *Scorecard* finds wide variation in quality measures across states. The highest performing states for the overall quality dimension—in order, Alaska, North Dakota, Hawaii, Minnesota, and Iowa—performed in the top or second quartile across most indicators. For example, Minnesota and Iowa scored consistently high on measures of quality of life in the community and quality of care in nursing homes, but ranked lower on measures of home health quality, and no data were available for nursing home quality in Alaska owing to the very small number of facilities in the state.[45]

QUALITY

Exhibit 14

State Ranking on Quality of Life and Quality of Care Dimension



Source: State Long-Term Services and Supports Scorecard, 2011.

The quality dimension reveals the strongest regional pattern, with the highest performing states concentrated in the upper Midwest and West, and the lowest performing states concentrated in the South (see Exhibit 14).

Quality of Life in the Community

The desire to remain in one's home is nearly universal, regardless of age or type of disability. Yet without needed services and supports, disability can severely affect a person's well-being and decrease quality of life. Furthermore, among working-age adults, the ability to find employment is a critical component of life quality.[46] Relatively low rates of employment by adults with disabilities compared to nondisabled adults can indicate inadequate services and supports needed to facilitate employment. A high-performing LTSS system ensures that people with disabilities who live in their own homes get the services and supports they need to maximize their health and function, to exercise choice and control, to maintain social connections and employment, and to sustain life satisfaction.

Social and Emotional Support

In 2009, only about two-thirds of adults with disabilities living in the community usually or always received needed social and emotional support. The percentage of individuals who

reported living with a disability and who usually or always received needed social and emotional support ranged from a high of 78 percent in Alaska to an average of 63 percent in the five lowest performing states.

Life Satisfaction

The *Scorecard* finds that life satisfaction among adults with disabilities averaged 91 percent in the top five states (South Dakota, Alaska, North Dakota, Hawaii, and Nebraska) and 81 percent in the five states reporting the lowest level of satisfaction among adults with disabilities. Thus, in the lowest performing states, about twice as many adults with disabilities were dissatisfied with life, compared with the highest performing states.

Rate of Employment

In all states, adults with disabilities are less likely to be employed than those with no disability. In particular, working-age adults with self-care disabilities have a very low rate of employment. In 2009, the overall proportion of adults ages 18 to 64 with ADL disabilities who were employed was only 17 percent, compared with 71 percent for those without ADL disabilities. This includes all people, even those not in the labor force, as people with disabilities are often not in the labor force, even though they may have the skills and desire to work. Because overall rates of unemployment vary considerably from state to state, this indicator reports the employment rate of working-age adults with ADL disabilities as a percentage of the state's rate of employment for working-age adults without ADL disabilities. Nationally, the employment rate of adults ages 18 to 64 with ADL disabilities was 24 percent of the rate of those without ADL disabilities.

The *Scorecard* finds that the relative employment of adults between the ages of 18 and 64 with a self-care disability ranged from a high of 57 percent in North Dakota to a low of just 19 percent in the five lowest performing states. The top five states averaged a 42 percent relative rate of employment, more than double the average of the bottom five states. The top states on this indicator (North Dakota, Montana, Alaska, Wyoming, and Nevada) are all very rural. It is possible that the higher rate of employment among people with disabilities in these states reflects different types of disability among their working-age populations. Working-age adults with the most severe disabilities may find it necessary to move to more urban areas, possibly in other states, in order to have more community integration.

Nursing Home Quality

As our nation has developed more alternatives to nursing homes for people with disabilities, in general, those who remain are likely to have the most severe disabilities, suffer from complex medical conditions, or have advanced dementia. As of 2004, some 1.4 million older people resided in nursing homes, a 29 percent reduction compared with 1989.[47] These factors make nursing home residents a vulnerable population whose physical, mental, and emotional condition can be highly dependent on the quality of care they receive.

Pressure Sores

Nursing home residents who receive inadequate care or who have limited mobility may develop pressure sores: areas of damaged skin that result from staying in one position for too long. Pressure sores can result in serious medical

complications, including severe, potentially life-threatening infection. The *Scorecard* finds that, on average, 12 percent of high-risk nursing home residents in the United States (including residents who cannot move or change position on their own and residents who do not receive or absorb needed nutrients) had pressure sores in 2008. An average of 16 percent of high-risk nursing home residents had pressure sores in the bottom five states: more than double the 7 percent average rate achieved by the top five states (Minnesota, New Hampshire, North Dakota, Nebraska, and Iowa). A lower rate of pressure sores indicates higher performance. It would take a 37 percent reduction in the national pressure sore rate among all states to reach the average achieved by the top five states.

Physical Restraints

Use of physical restraints on nursing home residents can contribute to increased prevalence of pressure sores, as well as social isolation and emotional distress. Despite progress since 1987, when federal legislation was passed giving nursing home residents the right to be free from physical restraint that is not required to treat medical symptoms,[48] 4 percent of long-stay nursing home residents were still physically restrained in 2008. While the percentage is small, it represents some 56,000 individuals. The *Scorecard* finds that physical restraints are rarely used in some states (less than 1 percent in Kansas), demonstrating that it is possible to reduce their use much further. The 7 percent average rate of use of physical restraints in the five bottom-performing states was more than five times the 1.3 percent average of the top seven states (Kansas, Nebraska, New Hampshire, Maine, Iowa, North Dakota, and Wisconsin).[49]

Staff Turnover

Excessive staff turnover in nursing homes can result in inconsistent and disruptive care, leading to potentially adverse health outcomes for residents. It also can be disorienting for patients with dementia. Yet turnover among frontline workers in nursing homes is high, almost 50 percent per year nationally. The *Scorecard* finds that the 74 percent average turnover rate in the bottom five states was nearly three times the 27 percent average rate reported by the top five states (Connecticut, Illinois, South Carolina, Rhode Island, and Hawaii).

The relationship between nursing staff turnover and quality of care is not simple to describe. Studies indicate that Licensed Practical Nurse (LPN) and Certified Nurse Assistant (CNA) turnover below 50 percent is not related to quality of care, whereas higher turnover rates do diminish quality. Turnover above 50 percent among Registered Nurses (RNs) did not appear to increase quality problems.[50]

In 2008, the average one-year nursing home staff turnover rate (the ratio of full- and part-time employee terminations that occurred during the year, regardless of cause, to the average number of active employees on the payroll during the same period) for all nursing staff was 49 percent. The five top-performing states reported LPN and CNA turnover rates ranging from 16 to 38 percent and RN turnover rates between 25 and 35 percent. The bottom five states reported LPN and CNA turnover rates ranging from 52 to 93 percent and RN turnover rates between 40 and 79 percent.

Hospital Admission

Among nursing home residents, hospital admission and readmission rates can be minimized. Hospitalizations can be reduced

through the provision of timely and effective preventive services, early treatment of acute illnesses, and effective management of chronic conditions. The *Scorecard* finds that, for the nation as a whole, 21 percent of long-stay nursing home residents were admitted to the hospital within six months of baseline assessment. On average, 29 percent of long-stay nursing home residents in the bottom five states had a hospital admission, nearly three times the 10 percent average rate achieved by the top five states (Minnesota, Utah, Arizona, Oregon, and Rhode Island). A lower rate of hospital admissions indicates higher performance.

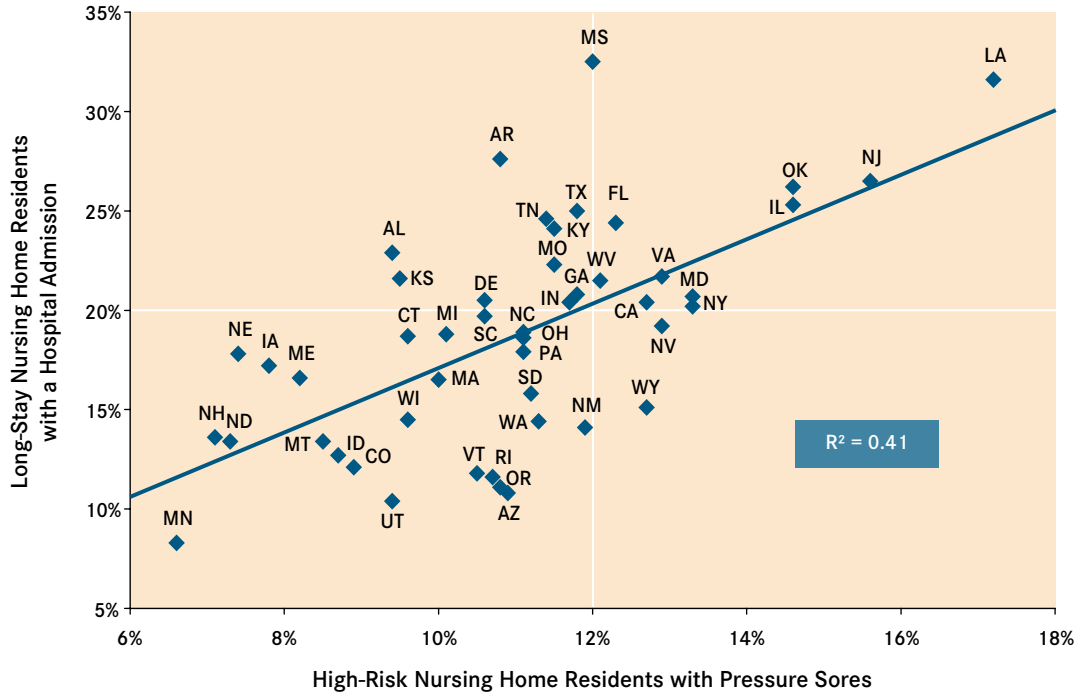
Better quality of care can be cost-effective as well. There is a strong correlation between occurrence of pressure sores and hospital admissions among long-stay nursing home residents (see Exhibit 15). Transitions between settings (e.g., nursing home to hospital), especially those that are caused by poor quality care, are both costly and often traumatic for LTSS users and their family caregivers.

Home Health Quality

Some people receive home health services for rehabilitation or recovery from an acute health episode and never enter the LTSS system. However, for many others, receipt of home health marks the beginning of their experience with the LTSS system, especially after an event such as a stroke in which full recovery may be

QUALITY OF LIFE AND QUALITY OF CARE Exhibit 15

Pressure Sores and Hospital Admissions from Nursing Homes



Data: Nursing home residents with a hospital admission—2008 Medicare enrollment data and MEDPAR file; Nursing home residents with pressure sores—2009 AHRQ National Healthcare Quality and Disparities Reports.
Source: State Long-Term Services and Supports Scorecard, 2011.

possible, but only after services of extended duration.

Pressure Sores

Home health agency staff should perform a number of procedures. Measures of the frequency of these best practices, such as the percentage of home health episodes of care in which interventions to prevent pressure sores were included in the physician-ordered plan of care for patients assessed to be at risk for pressure sores, are associated with better quality care and are important indicators of quality for all home health users, both short- and long-term.

The proportion of home health teams that included treatments to prevent pressure sores in the plan of care ranged from a high of 97 percent in Hawaii to an average of 81 percent in the five lowest performing states. The average across all states was 90 percent.

Hospital Admission

The primary role of home health is to provide post-acute and rehabilitative services, which may be of short or extended duration. Many people who receive skilled home health services (such as nursing or physical therapy) also require personal care or other services more commonly included as LTSS. Well-managed and coordinated care provided by home care agencies can minimize hospitalization and rehospitalization rates. Such care includes effective preventive and chronic care management as well as transition care when an individual is leaving a hospital or nursing facility. Thus, the performance of home health agencies is an important factor in quality.

The *Scorecard* finds that the national rate of hospital admissions for patients while they are receiving home health care averaged 31 percent in 2008. The 37 percent average hospitalization rate in the bottom-performing states was nearly two-thirds greater than the 23 percent rate of hospitalization reported by the top-performing states (Utah, District of Columbia, North Dakota, Washington, and Idaho). Fewer hospital admissions indicate better performance.

Dimension 4: Support for Family Caregivers

Family caregivers are a fundamentally important component of the LTSS system, even for individuals who also receive formal LTSS in their own homes or other settings. The term "family caregiver" is broadly defined in the *Scorecard* and refers to any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for an older person or other adult with a chronic or disabling condition. These individuals may live with or separately from the person receiving services.

In 2004, almost three-fourths (72 percent) of older people living in the community who received personal assistance relied *exclusively* on unpaid caregivers for help, and only 28 percent received supplemental assistance from paid services—down from 39 percent in 1994.[51] Services such as information and assistance, counseling, and respite care can help family caregivers navigate the LTSS system, avoid burnout, and therefore sustain their efforts.

In a high-performing LTSS system, supports are available to assist caregivers in their caregiving role and to help them maintain their own health and well-being. Thus, the physical, emotional, and financial problems and needs of family caregivers are identified

and addressed so that the LTSS system draws upon family caregivers without overstressing them. The resources and strengths of caregivers are recognized and respected, and supports are tailored to the individual caregiver's values, preferences, and situation. For example, their health status, work, and family responsibilities are considered. Caregiver supports are person- and family-centered: they recognize and support the wide range of roles family caregivers play in addition to providing LTSS. Formal services coordinate with family caregiving, and family members are included, when appropriate, in decision making and care planning, especially when the plan of care depends on a family caregiver.

The *Scorecard*'s dimension on support for family caregivers includes three indicators:

- The percentage of family caregivers who say that they usually or always get needed support.
- An indicator constructed from several factors including: the extent to which the state exceeds federal requirements under the Family and Medical Leave Act (FMLA), the state's paid family leave and mandatory paid sick leave provisions, its policies to prevent discrimination toward working caregivers, its policies on financial protection for the spouses of Medicaid beneficiaries who receive HCBS, and its assessment of and response to family caregiver needs.
- The number of important health maintenance tasks (from a list of 16 potential tasks) that can be delegated to LTSS workers, including medication administration and tube feedings. Delegation of these health maintenance tasks can provide significant relief to family caregivers.

The *Scorecard* finds the leading states in this dimension are Oregon, Washington, Arizona, Minnesota, and Iowa. In general, the highest performing states score in the top or second quartile across all three indicators, although there are exceptions. For example, Iowa is ranked just 28th on legal and system supports for caregivers. Although there are some exceptions, in general, the states west of the Mississippi River score higher than do states to its east (see Exhibit 16).

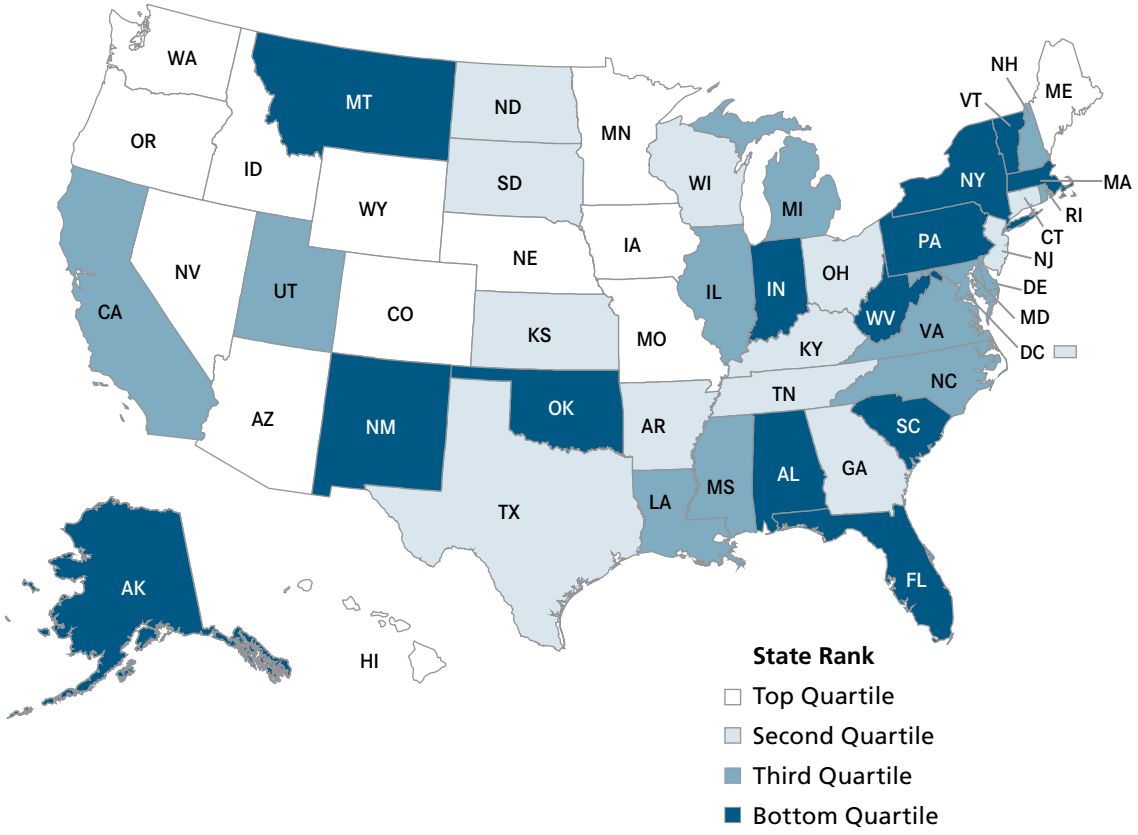
When budgets are tight, it may be difficult for states to fund services that support caregivers. Yet failing to do so may be counterproductive in the long run. The economic value of family caregiving was estimated at $450 billion in 2009, four times the total amount of Medicaid spending on LTSS.[52] If family caregivers do not receive needed respite from their responsibilities, they are more likely to burn out and reduce their efforts. The result would likely be greater demand for the publicly funded programs that provide LTSS. Moreover, states should recognize that legal system supports for family caregivers may play a critical role in helping them to maintain their caregiving role and still hold down a job.

Getting Needed Support

Many caregivers are spouses, some with their own health issues. Others are daughters and sons, more than half (58 percent) of whom are trying to hold down a job, sometimes taking care of their own children as well.[53] While most family caregivers undertake this work willingly, their compromised health, financial burdens, and accumulated strain over time often are

SUPPORT FOR FAMILY CAREGIVERS Exhibit 16

State Ranking on Support for Family Caregivers Dimension



Source: State Long-Term Services and Supports Scorecard, 2011.

overlooked. These burdens and health risks can impede family caregivers' ability to provide care, lead to higher health and LTSS costs, and affect the caregivers' quality of life as well as that of the people for whom they care. Thus, it is critical that a high-performing LTSS system recognize, respect, and support family caregivers. States can mitigate the complexities and strains of family caregiving by providing supportive services, respite, or education and training.

In 2009, on average, 77 percent of family caregivers said that they usually (32 percent) or always (46 percent) received needed social and emotional support. The proportion who reported providing regular care or assistance to a friend or family member and who usually or always received needed social and emotional support ranged from a high of 84 percent in Oregon to an average of 72 percent in the five lowest performing states.

Legal and System Supports

This indicator is constructed from several measures: state family medical leave laws; mandatory paid family and sick leave; protection of caregivers from employment discrimination; the extent of financial protection for the spouses of Medicaid beneficiaries who receive LTSS; and caregiver assessments. Appendix A12 presents state scores on the entire composite and for each component.

The top five states on this indicator are Oregon, the District of Columbia, Washington, Illinois, and California. Though it is possible for states to score as high as 12 on the composite, the highest score was only 6.43, as many supports for family caregivers are available only in a small number of states or localities.

The Family and Medical Leave Act of 1993 (FMLA) allows covered workers to take up to 12 weeks of unpaid leave in a year to care for themselves or for a parent, spouse, or child with a serious health condition.[54] The Act protects the worker's continued employment status and health insurance coverage. While the federal statute must be enforced in every state, some states exceed the minimum requirements by broadening the range of employers that must comply with its requirements, extending the number of weeks of coverage, or allowing a more inclusive definition of "family member." In 2009, only one-quarter of states exceeded the federal minimum FMLA by covering a broader range of employers and employees and permitting longer leave periods or type of leave. The five states that most exceeded the federal FMLA provisions were the District of Columbia, Oregon, Washington, Vermont, and Maine.

While the FMLA does not require employers to offer *paid* sick leave, it does require covered employers to offer up to 12 weeks of *unpaid* leave for an illness, treatment for an illness, or to care for family members. Currently there are no federal laws that require private sector employers to provide paid sick leave benefits. Only two states (California and New Jersey) have enacted paid or partially paid family leave provisions that include elder care, while only the District of Columbia has enacted mandatory paid sick leave provisions, as of 2008.

As of 2010, only the District of Columbia has laws that expressly address family responsibilities as a protected classification in the context that prohibits discrimination against employees who have family responsibilities, including providing care to aging parents or ill or disabled spouses or other family members. Only five other states (Oregon, Illinois, Michigan, Colorado, and Maryland) have laws that address family responsibilities as a protected classification; however, these laws are not statewide.

In 2010, only one-quarter of states used the maximum federal spousal protection of $2,739 in monthly income and $109,560 in assets as the state's floor of protection (Alaska, California, Colorado, Georgia, Hawaii, Illinois, Iowa, Louisiana, Massachusetts, Mississippi, Rhode Island, Tennessee, and Wyoming) when a spouse qualifies for nursing home care under Medicaid. With the exception of Massachusetts, these states also allowed spousal protection for HCBS recipients.

States are beginning to recognize, respect, assess, and address family caregiver needs. In 2010, 11 of the 47 states responding to the AARP survey reported that they assess family caregivers for depression, physical health, and the level of strain they experience and use the information to develop a plan of care, to educate and train on skills to provide care, to authorize services to caregivers, and to authorize respite care. Nineteen other states have a caregiver assessment that performs some of these functions; the remaining 17 states do not assess or address caregivers' needs.

Nurse Delegation

The final indicator in this dimension examines state laws regarding consumers' ability to get assistance with health maintenance tasks. Consumers who are directing their own workers may be able to get this help more easily than those who have workers hired by agencies. State Nurse Practice Acts usually determine the extent to which direct care workers can provide assistance with a broad range of health maintenance tasks.[55] Technically, this is known as "nurse delegation." The National Council of State Boards of Nursing conducted a survey of state boards of nursing for AARP, and the state's score is based on 16 tasks, including administration of various types of medications, ventilator care, tube feedings, and other kinds of help that many people with chronic, stable conditions require to be able to live outside of institutions. Appendix A14 presents a complete list of the tasks included in this indicator, and which states permit them to be delegated.

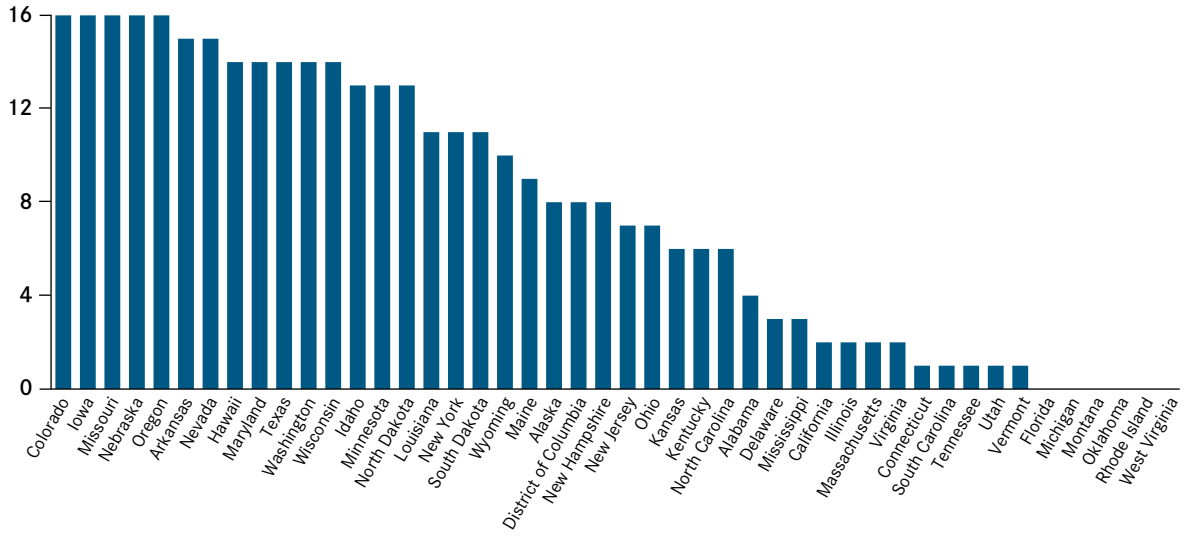
This indicator is critical for family caregivers. In general, a state will permit family members to be trained to perform health maintenance tasks, but may not allow paid direct care workers to be taught to perform them. Thus, family caregivers may have to rush home from work at lunchtime to administer medication or a tube feeding that a paid caregiver is not authorized to do. Hiring a nurse to perform these routine procedures, typically performed several times a day, would not be feasible. Therefore, allowing nurses to train and delegate these tasks to direct care workers can ease the burden on family caregivers.

The *Scorecard* finds that the five top-performing states (Colorado, Iowa, Missouri, Nebraska, and Oregon) allowed all 16 tasks to be delegated. By contrast, in the bottom six

SUPPORT FOR FAMILY CAREGIVERS Exhibit 17

State Policies on Delegation of 16 Health Maintenance Tasks

Number of tasks allowed to be delegated



Note: Data not available for Arizona, Georgia, Indiana, New Mexico, and Pennsylvania.
Data: National Council of State Boards of Nursing, 2011 Nurse Delegation Survey.
Source: State Long-Term Services and Supports Scorecard, 2011.

states, none of the 16 tasks could be delegated (see Exhibit 17). Across all states, the median number of tasks that states allowed nurses to delegate was 7.5. Lower ranked states can learn from the top performers that delegation of these tasks to direct care workers is possible and supports consumers' choice to live in the community.

ROLE OF PUBLIC POLICY AND PRIVATE SECTOR

Public policy plays an important role in LTSS systems by establishing who is eligible for assistance, what services are provided, how quality is monitored, and the ways in which family caregivers are supported. Its role is especially critical because the cost of services exceeds the ability to pay for most middle-income families. The *Scorecard* is a tool to help states improve their LTSS systems. However, the degree to which state policymakers directly affect an outcome varies across the indicators. Performance on some indicators may be directly affected by the actions of state policymakers—the governor, state agencies, and state legislators. On other indicators state policy has an important, but less direct influence; private sector actions, economic conditions, and demographic variables in the state will also affect performance. State policy has the most direct control over the following indicators:

- The reach of the state's Medicaid program for people with disabilities who have low incomes;
- The reach of the state's Medicaid LTSS for people with disabilities who have low incomes;
- The functionality of the state's ADRC or single entry point system to help people find and access services;
- The proportion of Medicaid and state LTSS funds that support HCBS;
- The proportion of new Medicaid LTSS beneficiaries who use HCBS;
- The proportion of participants in publicly funded LTSS programs who direct their own services;
- The effectiveness of the state's tools to facilitate choice (such as programs to divert or transition LTSS users from nursing homes and into the community-based settings they choose);
- Legal and system supports for family caregivers; and
- Nurse delegation practices for consumers to get help with health maintenance tasks such as medications.

Areas for Public Policy Action

The following examples illustrate ways in which public policy action can lead to improvements in state performance.

Medicaid safety net

State policymakers have substantial control over Medicaid policies that determine the types of LTSS services offered and the settings in which they are provided. States have substantial control over establishing financial eligibility standards for Medicaid coverage as well as the level of disability needed to qualify for services. These decisions can either encourage or discourage access to HCBS. States that take advantage of options to expand eligibility

increase both access and choice for older people and adults with disabilities. Because the cost of LTSS is high, state Medicaid policies may enable people who cannot afford to pay for services on their own to access them through Medicaid. States can take advantage of new opportunities offered by the *Affordable Care Act* to improve their LTSS systems.

LTSS "balancing"

This is an area over which state governments have tremendous control and, through their public policies, can make considerable strides in ensuring that people who need LTSS can choose noninstitutional options for care. States that have improved the balance of services away from institutions and toward HCBS have taken advantage of Medicaid optional services such as HCBS waivers and the Personal Care Services option. States also can pursue new opportunities offered by the *Affordable Care Act* to improve the balance of their LTSS systems.

Maximizing consumer choice of LTSS options

State policies such as options counseling and nursing home diversion programs can help to direct new LTSS users toward HCBS rather than nursing homes. States also can implement presumptive eligibility procedures to quickly establish that a person will be able to qualify for public support for HCBS, thereby preventing unnecessary nursing home admissions.

Fully functioning ADRC or single entry point systems play a critical role in helping people of all incomes and types of disability to access LTSS information and services. States with more effective systems will expand access to HCBS services.

Consumer direction

States have great flexibility to give people who use LTSS the option to direct their own services in publicly funded programs. These programs often allow participants to have greater flexibility as to when services are delivered and who provides them. Such programs also can expand the available workforce, as many participants choose to hire family members who would not otherwise be working in this field.

Nursing home residents with low care needs

Taking advantage of federal grants such as Money Follows the Person can help states to move nursing home residents who want to return to the community into their own homes or apartments.

Pressure sores among nursing home residents

States have the responsibility to establish and enforce high standards for providers and effectively monitor the quality of care nursing homes provide. Every state is funded to operate a nursing home ombudsman program, but each state determines how frequently the ombudsmen visit each facility, how they respond to complaints, and the methods they use to monitor quality. State nursing home inspectors have a major role in enforcing federal directives to reduce pressure sores, and states can use quality bonuses to reward providers who demonstrate significant progress.

Preventing hospitalizations

Some states are beginning to develop more coordinated service delivery systems that integrate primary, acute, chronic, and long-term services. Integrated approaches such as PACE have a proven record of improving outcomes and reducing the use of institutions.

Nurse delegation

State policy directly determines what health-related tasks can be delegated. This difference will have a major impact on family caregivers. Unlike some policy changes that may cost states money and are therefore more challenging to implement, changing nurse practice laws will, if anything, save money in public programs by broadening the type of workers who can safely perform these tasks.

Areas for Public and Private Sector Actions

Some areas of performance involve both public and private sector actions. For example, quality of life and quality of care cannot be legislated, or determined entirely by policy.

Nursing home quality

State policy regarding best practices, inspection, and oversight can have a significant effect on quality of services. For example, the nursing home survey and certification process can affect the number of residents with pressure sores and the number who are physically restrained. It can identify nursing homes with performance problems, and state follow-up can insist on appropriate and timely action to remedy deficiencies in care quality. But the facilities themselves must take steps to ensure high quality.

Nursing home staff turnover

Staff turnover is another factor that is related to providing high-quality care. By striving to raise wages, improve working conditions, and offer benefits, states can help to improve staff retention in nursing homes and home health care agencies. Doing so will improve continuity of care for LTSS beneficiaries. But the private sector also plays a critical role in retaining workers in LTSS settings. Innovative delivery models, such as the "Green House," have improved retention of frontline staff by giving them more autonomy in providing services.[56]

Private long-term care insurance

Private long-term care insurance can help some individuals who meet underwriting requirements afford more LTSS, and the reach of these policies is largely determined by the private market. But state tax incentives to purchase private insurance and the Long Term Care Insurance Partnership program, which was designed to help purchasers protect some of their assets should they eventually qualify for Medicaid, may influence the purchase of private insurance coverage. Employers who offer or subsidize the purchase of private LTCI also play a role.

MAJOR FINDINGS

The states that ranked at the highest level across all four dimensions of LTSS system performance, in order, are Minnesota, Washington, Oregon, Hawaii, Wisconsin, Iowa, Colorado, and Maine. These eight states performed markedly better than even the other states in the top quartile (Kansas, District of Columbia, Connecticut, Virginia, and Missouri), all of which scored in the top quartile on only the affordability/access dimension. All four measured dimensions are positively correlated, suggesting an underlying consistent pattern of systemwide performance; however, there is significant variation among states.

Eight major findings emerge from the *Scorecard*:

Leading states often do well in multiple dimensions—but all have opportunities to improve

The leading states generally score in the top half of states across all dimensions. Public policy decisions made in these states interact with private sector actions, resulting in systems that display higher performance. But no state scored in the top quartile across all 25 indicators, demonstrating that every state's LTSS system has at least one indicator on which it trails the standards set by top states. Even within dimensions, there is only one instance in which a state ranked in the top quartile across every indicator in the dimension.

Responsibility for performance in the four dimensions varies. Changes in state policy can have a very direct influence for some indicators, while improvement in other dimensions is affected more by individual LTSS users, providers, and economic and other factors over which state governments have only indirect control.

Poverty and high rates of disability present challenges

Lagging states scored in the bottom half of states on most dimensions. Among states in the bottom quartile overall (Mississippi, Alabama, West Virginia, Oklahoma, Indiana, Kentucky, Tennessee, Florida, Louisiana, Georgia, New York, and Nevada), many are in the South and have among the lowest median incomes and highest rates of both poverty and disability in the nation. This pattern largely holds across all dimensions. Among southern states, only Virginia and North Carolina rank in the top half overall.

Although economic factors appear to have some relationship to state performance, there are many exceptions. For example, New Hampshire, Massachusetts, and Utah all have state median incomes at least 20 percent above the national median income, yet they rank in the lower half of states. Maine, Kansas, and Missouri rank in the top quartile, despite having state median incomes slightly below the national median.

Many states have opportunities to improve

States that ranked in the second quartile (Nebraska, Arizona, California, Alaska, North Dakota, Idaho, Vermont, Wyoming, New Jersey, Illinois, Maryland, North Carolina, and New Mexico) all scored in the top quartile on at least one dimension. With the exception of Alaska (an unusual state because of its unique geography), no state in the second quartile scored in the bottom quartile on more than one dimension. These states all have areas of success, and can also improve to a higher level of performance by targeting their efforts in areas where they lag, and where the path to higher performance has been demonstrated in other states.

The *Scorecard* should be an especially useful tool to states that perform well in some but not all areas of LTSS system performance. For example, California, New Mexico, and North Carolina all scored in the top quartile in both the affordability and access and choice dimensions, yet their performance was brought down by scoring in the third and fourth quartiles on the quality and support for family caregivers dimensions. The reverse pattern was seen in Nebraska, North Dakota, and Wyoming, which scored high on the quality and caregiving

dimensions, but low on affordability and access and choice.

Wide variation exists within dimensions and indicators

Wide variation exists within all dimensions, with low-performing states being markedly different from those that score high. In many cases, low-performing states have not adopted public policies that increase their access to services or that enable consumers to exercise choice and control. Substantial variations also are found in the quality of service delivery, and in measures of support for family caregivers.

There is a particularly wide spread on the extent to which states facilitate self-direction (the ability of consumers to hire and manage a worker of their choice and set hours worked and tasks performed). In California, long a leader in this area, 143 people per 1,000 adults with disabilities use self-direction—more than six times the national average. Nearly two-thirds of all consumer-directing individuals in the country live in California.

Similarly, state variation in nurse delegation practices—permitting home care aides to perform designated health maintenance tasks—spans all 16 tasks on which states were ranked. Five top states allowed delegation of all 16 tasks, and six bottom states allowed none.

State Medicaid policies dramatically affect consumer choice and affordability

Medicaid is the primary source of public funding for LTSS. It plays a leading role in determining the extent to which low-income older people, people with disabilities, and their families receive support through HCBS. It also affects the extent to which people with LTSS needs who want to avoid entering nursing homes are able to do so, by facilitating or hindering the choice of alternative settings, such as assisted living. States have direct control over spending priorities, and some states have led the way to improve access and choice in Medicaid. These policy decisions are reflected in the proportion of Medicaid LTSS spending that states devote to HCBS and their success in supporting new program participants' choice of HCBS, as opposed to nursing homes.

State performance on the percentage of Medicaid and state-funded LTSS spending for older people and adults with physical disabilities that pays for HCBS ranges from a low of 11 percent in North Dakota to a high of 64 percent in New Mexico. States' ability to serve new Medicaid LTSS participants in HCBS, as opposed to nursing homes, ranges from a low of 22 percent in Indiana to a high of 83 percent in Minnesota.

Support for family caregivers goes hand in hand with other dimensions of high performance

The *Scorecard* reports on assistance for family caregivers by assessing whether they are receiving needed support and by examining state laws that can aid them. The most meaningful support for caregivers may be a better overall system that makes LTSS more affordable, accessible, and higher quality with more choices. Thus, high scores on access, affordability, and choice may reflect states' recognition that caregivers are essential and that policies that aid them include building a strong overall system. Very few states that score highly on support for family caregivers score poorly on other dimensions, and few states that score poorly on the caregiving dimension are ranked in the top quartile overall.

States can improve their performance by exceeding the federal requirements for the FMLA and mandating paid sick leave to help working family caregivers, as well as preventing impoverishment of the spouses of Medicaid beneficiaries who receive HCBS. States also can implement programs to assess the needs of family caregivers and provide respite care and other services to support their ongoing efforts.

Better data are needed to assess state LTSS system performance

At this time, limited data make it difficult to fully measure key concerns of the public and of policymakers, including the availability of housing with services, accessible transportation, funding of respite care for family caregivers, and community integration of people with disabilities. Improving consistent, state-level data collection is essential to evaluating state LTSS system performance more comprehensively. Most critically, an important characteristic of a high-performing LTSS system identified by the *Scorecard* team—how well states ensure effective transitions between hospitals, nursing homes, and home care settings and how well LTSS are coordinated with primary care, acute care and social services—cannot be adequately measured with currently available data.

Some states are making strides in coordinating services, for example through programs that integrate Medicare and Medicaid services or that address critical transitions between hospitals, nursing homes, and the home. However, good data are not available to measure the coordination of services in a way that is comparable across states. Consistent definitions of respite care, a critical support for family caregivers, as well as comprehensive data on the amount and type of respite care provided, would add strength to the caregiving dimension.

Adequate measures of HCBS quality, consistent across the states, are another significant data gap. Quality measures in the *Scorecard* include indicators of quality of life for people with disabilities in the community, and indicators of quality of care only for the most formal of LTSS: nursing homes and home health. Ideally, quality of care would include consumer and family experiences with the full range of HCBS, including adequacy of care plans, timely delivery of services, cultural competency, and other indicators. However, comparable data across states are not available. CMS offers guidance to the states regarding HCBS quality measures, but states are not required to use standardized measures, nor is there a national database that contains information about performance on the measures in all states. Currently there are several ongoing initiatives to develop measures of HCBS quality: efforts of the Agency for Health Care Research and Quality, the National Balancing Indicators project, the Money Follows the Person program, and the National Quality Enterprise.[57]

It is our hope that improved data collection will enable future *Scorecards* to expand upon on the strong set of foundational indicators in this initial *State LTSS Scorecard*, and provide a more complete and comprehensive analysis of LTSS system performance in the future.

The cost of LTSS is unaffordable for middle-income families

The cost of services, especially in nursing homes, is not "affordable" in any state. The national average cost of nursing home care is 241 percent of the average annual household

income of older adults. Even in the five most affordable states, the cost averages 171 percent of income, and in the least affordable states it averages an astonishing 374 percent. When the cost of care exceeds median income to such a great degree, many people with LTSS needs will exhaust their life savings and eventually turn to the public safety net for assistance.

Though less extreme, the cost of home health care services also is unaffordable for the typical user, averaging 88 percent of household income for older adults nationally. People who receive home care services must add these costs to all their other living expenses. If they cannot afford the home care services they need, they may place added burdens on family caregivers, who most likely already are providing services.

IMPACT OF IMPROVED PERFORMANCE

States can improve their LTSS system performance in numerous ways. Improvement to levels achieved by top-performing states would make a difference to the more than 11 million adults who have LTSS needs[58] and their 62 million family caregivers[59] in terms of access, choice, and quality of care (see Exhibit 18).

If all states' public safety nets were as effective as that of Maine in covering low-income people with disabilities, an additional 667,171 individuals would receive coverage through Medicaid or other public programs. Such coverage would link people with disabilities and limited incomes to health care as well as LTSS.

States that effectively direct people in public programs with LTSS needs to HCBS can address the preferences of consumers in a cost-effective manner. If all states rose to Minnesota's level of performance in this measure, 201,531 people could avoid costly and unnecessary nursing home use.

Many nursing home residents with low care needs can be, and would prefer to be, served in the community. If all states achieved the rate found in Maine, 163,441 nursing home residents

Exhibit 18

National Cumulative Impact if All States Achieved Top State Rates

Indicator	If all states improved their performance to the level of the best-performing state for this indicator:	
Low-Income PWD with Medicaid	667,171	more low- or moderate-income (< 250% poverty) adults age 21+ with ADL disabilities would be covered by Medicaid.
Medicaid LTSS Balance: New Users	201,531	more new users of Medicaid LTSS would first receive services in home and community settings.
Home Health Aide Supply	2,674,428	more personal care, home care, and home health aides would be available to provide LTSS in the community.
Nursing Home Low Care	163,441	nursing home residents with low care needs would instead be able to receive LTSS in the community.
Nursing Home Hospital Admissions	120,602	unnecessary hospitalizations of people in nursing homes would be avoided.

Notes: PWD = People With Disabilities; ADL = Activities of Daily Living.
Source: State Long-Term Services and Supports Scorecard, 2011.

with low care needs would instead be able to receive LTSS in the community.

Excessive transitions between care settings such as nursing homes and hospitals reflect poor coordination of services, and are correlated with poor quality of care. If all states matched the performance of Minnesota, 120,602 hospitalizations could be avoided, saving an estimated $1.3 billion in health care costs.

RAISING EXPECTATIONS: THE NEED FOR ACTION TO IMPROVE PERFORMANCE

> *Over the next few years, the United States in effect will choose between creating a nationwide, high-performing system of long-term services and supports or abandoning that goal.*[60]

This *State LTSS Scorecard* is being released as the nation grapples with the far-reaching effects of a sustained economic downturn. As family incomes shrink, demand for publicly funded services goes up—just when states are least able to expand programs because of decreases in general revenue that often fund the state's portion of LTSS. Congress, in the *Affordable Care Act*, offered states "carrots" to support improvements in their LTSS systems, rather than "sticks" to punish them for underperformance.[61] The *Affordable Care Act* can directly help states achieve higher performance in several areas, including:

Choice of Setting and Provider—State funding for HCBS continues to be outpaced by nursing home spending in most states. Achieving a better balance between these modes of service delivery is a critical component in a high-performing system. The *Affordable Care Act* provides financial incentives for states through provisions known as Community First Choice, Balancing Incentives Payment Program, and Money Follows the Person. Low-performing states have the most to gain by taking advantage of these provisions. Given the tremendous range in states' public spending on HCBS, low-performing states should examine the policies that have helped high-performing states to make major strides in offering people who need LTSS the choices they want.

The bottom states are spending less than 15 percent of their Medicaid and other public LTSS dollars for HCBS. Compared with top states (which spend, on average, 60 percent of these dollars for HCBS), these states clearly have substantial room for improvement. Moreover, the top-performing states, through the policies they have adopted, demonstrate that gains in facilitating consumer choice are achievable.

Enormous range in performance also is illustrated in states' record of serving new LTSS participants in HCBS, rather than nursing homes. States that make a commitment to facilitate the delivery of services in HCBS in a timely manner will find that, over time, they develop more cost-effective systems. In the long run, these states can serve more people at lower cost. In the top-performing states, people who need LTSS are three times more likely to get services in HCBS before ever using a nursing home than they are in the bottom states.

Access—The *Affordable Care Act* expanded funding for states to develop ADRCs—one-stop locations that are designed to provide comprehensive information and assistance to

people of all incomes and types of disability.[62] All too often, the need for LTSS takes individuals and their families by surprise, and they are unprepared for the challenges in locating and paying for services. Whether one is paying for services out of pocket, receiving care from a family member, or turning to public programs, certain problems are nearly universal. Finding all the information one needs in a single convenient, accessible location can be very difficult. A high-performing system can mitigate the strain that families face by developing effective single entry point or no wrong door information and referral systems.

This *Scorecard* ranked states on 12 measures of effectiveness for their ADRC/single entry point systems. States spanned nearly the entire spectrum for their system effectiveness in this area—from a low of 1 point to a high of 11 points on a 12-point scale (most states were between 5 and 10 points). Low-performing states can learn from high performers that it is possible to develop effective programs to help consumers easily access information and services.

A promising development is the enactment of the Community Living Assistance Services and Supports program or CLASS—a provision of the *Affordable Care Act*. When implementation begins in 2012, adults in the workforce will have the opportunity to enroll in a public LTSS insurance program. Workers who pay premiums for at least five years will qualify for a cash benefit if they meet the program's disability requirements. Unlike private LTCI, which has medical underwriting criteria, employed people with disabilities will be eligible to enroll in CLASS and receive cash payments that can help them afford LTSS. In the future, people who enroll in CLASS will have the security of knowing that, if they develop a disability, a cash benefit will be available to help them afford LTSS using the setting and provider of their choice. States have an important role to play in publicizing this program, as do employers.

Finally, family caregivers are the glue that holds together the entire LTSS system. Many people who need LTSS never pay for services or turn to public programs. Nor have most had the resources or foresight to purchase private LTCI. Instead, they rely on family members or close friends to help them with daily activities. The economic value of family caregivers exceeds total Medicaid spending in every state, and dwarfs the states' portion of Medicaid spending on LTSS. These caregivers need and deserve support from state programs, or they risk burning out and jeopardizing their own health and economic security.

Several states exemplify innovative approaches that have resulted in high performance. In particular, key features were identified in states that rank high on the indicators over which state government has a high level of control. For example:

- Minnesota, which ranked number one overall and scored in the top five on all four dimensions, developed two services that help consumers understand all their LTSS options. The ADRC serves as a single point of entry system available through the LinkAge Service Line. This statewide, county-based system assesses functional and financial eligibility for public entitlement programs. An online automated tool allows consumers and staff of different resource centers to access the same information through a Web interface. Resource Center staff also offer

programs and services in public places (e.g., libraries, faith-based organizations, grocery stores).

Long-Term Care Consultation Services are available through county human service agencies and include a variety of services designed to help people make decisions about LTSS. County teams of social workers and public health nurses provide information and education about local LTSS options, an in-person visit to assess needs and develop care plans, information about the public programs that may help people pay for services, and transition assistance for people who want to return to community settings.

- Washington's LTSS system has several features that contribute to its number two ranking. One agency, the Aging and Disability Services Administration (ADSA), is responsible all LTSS functions—licensing, financial and functional eligibility, care management, and institutional, residential, and HCBS. The budget process allows ADSA to allocate funds to HCBS, residential settings, or nursing homes as needed. A standardized, automated assessment instrument is used across all settings. Care managers—registered nurses or social workers—contact nursing home residents who have been admitted from a hospital within seven days of admission to explain the residential and community options available. Individuals admitted from a community setting who are Medicaid beneficiaries, or are likely to become Medicaid beneficiaries within 180 days, receive a preadmission assessment and options counseling.
- Oregon ranked third overall and first on the caregiving dimension. Through the Oregon Family Leave Act, it exceeds provisions of the FMLA, offering unpaid leave to a broader definition of working family caregivers. Under the FMLA, a family member includes a son, daughter, spouse, or parent. In Oregon, family member also includes the employee's grandparent, parent-in-law, same-sex domestic partner, or grandchild. In addition, Oregon covers workers in smaller businesses, requiring employers with 25 or more employees to guarantee 12 weeks of unpaid leave annually, compared with employers with 50 or more employees under the FMLA.[63] In addition, Oregon has had broad nurse delegation policies for three decades.[64]
- Wisconsin, ranked fifth overall, has been at the forefront of LTSS reform, in large part through its managed care programs. Family Care Partnership, a managed care program for older adults and people with disabilities, provides a wide range of LTSS options. As of December 2009, nearly 28,000 people were enrolled in 48 of Wisconsin's 72 counties. In addition to PACE, Family Care Partnership integrates both Medicare and Medicaid funding for primary, acute, and LTSS. Combined Family Care Partnership and PACE enrollment was more than 5,000.[65]

  Wisconsin also provided the national model for the ADRC. Consumers and their families can receive information, referrals, help with public assistance, and LTSS options and benefits counseling at the ADRC, via the phone, or through a home visit.

- Kansas ranked ninth overall, largely because of its high rank on measures of affordability. In particular, private pay affordability for nursing facilities and relatively greater coverage through private long-term care insurance helped to boost its ranking. Kansas also demonstrated attention to quality through its nursing home pay-for-performance program and increased ombudsman monitoring. These actions may explain the state's number one ranking on the number of nursing home residents who are physically restrained. Kansas also has relatively high rankings on two Medicaid measures: access to Medicaid LTSS (ranked 14) and balancing of Medicaid LTSS toward HCBS (ranked 17). These rankings may reflect state action to reduce the number of nursing home beds, offsetting this reduction with increased Medicaid HCBS funding.
- Missouri ranked thirteenth overall, largely because of its high rank on measures of affordability and support for family caregivers. Like its neighbor Kansas, Missouri demonstrated comparatively greater private pay affordability for nursing facilities, relatively greater coverage through private long-term care insurance, and high access to Medicaid LTSS (ranked tenth). Missouri nurse practice laws allow nurses to delegate all 16 health maintenance tasks on which states were ranked, contributing to its number nine rank in providing support for family caregivers. Missouri also demonstrates support for family caregivers through its spending on programs that provide respite services.
- Vermont's Choices for Care (CFC) program expands choices for older adults and individuals with physical disabilities, leading to its number four rank in the choice dimension. This Medicaid §1115 Demonstration Program operates under a global budget. This means that a single budget is used to fund all LTSS, regardless of setting. Other state Medicaid programs have an institutional bias—that is, people who qualify for Medicaid are entitled to receive nursing home services, but HCBS is offered as an option.

  CFC serves three groups. Highest need individuals have an entitlement to HCBS or nursing home care based on the consumer's preference. High-need individuals are eligible for HCBS or nursing home care as funds are available. Moderate-need individuals may receive care management, adult day services, and homemaker services as funds are available. CFC includes a Flexible Choices option through which consumers receive an allowance based on their needs and the value of their CFC Home Based Service Plan. Consumers work with a Flexible Choices consultant to create a budget that uses the allowance in a way that best meets their needs.

  The number of individuals receiving HCBS and services in residential settings increased 60 percent between October 2005 and March 2011, while the number of nursing home residents dropped 15 percent during the same period. LTSS expenditures were 21 percent below the cap set by CMS for the period.

In a high-performing LTSS system, one would want to see coordination across health, LTSS, and social/supportive services, including

caregiver support. Although several states operate managed care programs that coordinate primary, acute, and LTSS, data are not available to determine whether top-performing states have implemented such measures. Given the innovative programs to support system integration that were enacted as part of the *Affordable Care Act*, we hope that future *Scorecards* may report on emerging practices in this area and that this *Scorecard* will spark future federal and state action.

CONCLUSION

The *Scorecard* finds wide variation across all dimensions of state LTSS system performance. Part of this variation is attributable to the fact that the United States does not have a single unified approach to the provision of LTSS. The primary public program that funds LTSS is Medicaid: a federal-state partnership that gives states substantial flexibility to determine who is eligible for LTSS, how LTSS are accessed, what services will be provided, what the payment rates will be, and where services will be delivered. This flexibility provides opportunities to learn from creative approaches to delivering services, yet results in disparities on what support is available to frail older people and low-income people with disabilities. State and federal programs have a clear opportunity and need to raise the floor so that the state of residence does not put people who need LTSS at risk.

The *Affordable Care Act* offers states promising new incentives for improving their LTSS systems, and the lowest performing states have the most to gain by taking advantage of these new provisions. Raising expectations for underperforming states is both reasonable and necessary. The Supreme Court in the Olmstead decision affirmed the right of people with disabilities to live in the least restrictive environment appropriate to their needs.[66] States with fewer HCBS options through their Medicaid programs can learn from leading states that providing a broader array of these services can be cost-effective as well as responsive to the needs and preferences of older adults and people with disabilities.

Geography should not determine whether people who need LTSS have a range of choices for affordable, high-quality services. All Americans should share a unified vision that supports the ability of older people to age in homes of their choice with dignity and the support they need to maximize their independence. The lives of people with disabilities should be integrated into the community, where they can maintain social connections, engage in productive employment, and contribute to the rich diversity of American life.

By definition, people who need LTSS depend on others to help them perform tasks of daily living. They should be able to expect that this help will be of high quality and delivered in a way that allows them to sustain a high quality of life. They should also have access to full community participation and employment, which are important to quality of life. Most older adults prefer to have family members engaged in providing LTSS when possible.[67] Thus, family members are an important and increasingly valued part of the LTSS system. A high-performing system supports family caregivers as well as care recipients.

Across our nation, people with disabilities are struggling to afford the services they need to maintain their independence and quality of life, and to receive services in the settings,

and from the providers, they prefer. Families are struggling with the challenge of caring for spouses, parents, grandparents, and other relatives whose health is failing, who have become frail, or who suffer from dementia. They provide hours of care, often while also trying to hold down a job or raise their children. They are the foundation of our nation's LTSS system, but they need help. They need somewhere to turn for information, support, and respite. As the nation ages and future generations have fewer children on whom to rely for support, a more adequate system of LTSS will be critical to ensure that older adults and people with disabilities can get the help they need.

Building that improved system must begin now. Without action to improve performance, people will be needlessly confined to nursing homes because community-based alternatives do not exist in their state. Caregivers will burn out and imperil their own health and economic future. Families will bankrupt themselves paying for care because affordable alternatives do not exist. LTSS systems in all states have room and need to improve in some areas. In some states the need for improved performance spans all dimensions. But improvement is possible, and in many cases, the successes achieved by leading states have already shown the way. It is time to raise expectations for LTSS performance. We must move to become a nation in which older people and those with disabilities are given meaningful choices, have access to affordable, coordinated services, a high quality of life and care, and support for their family caregivers regardless of the state they live in.

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Appendix B

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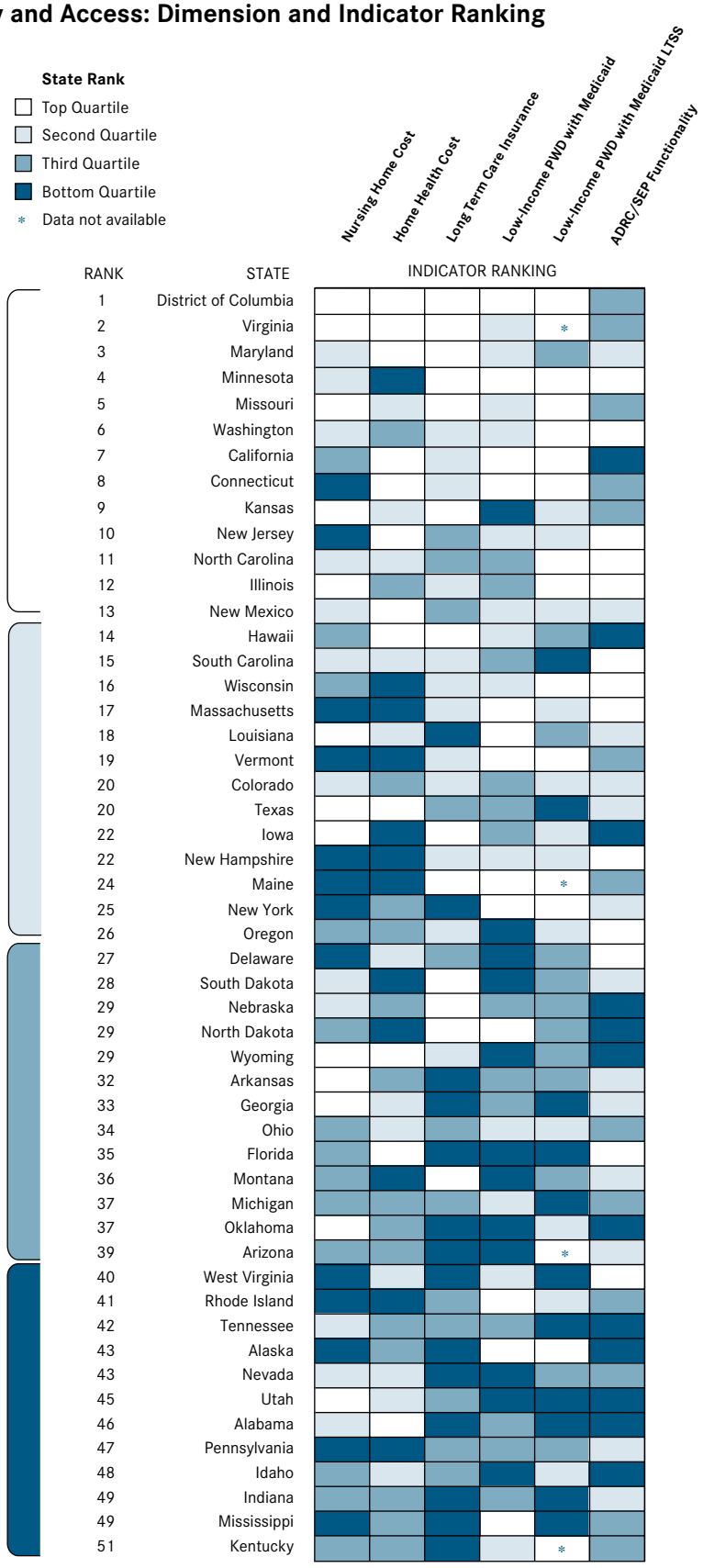
Exhibit A1

Summary of Indicator Rankings by State

Overall Rank*	State	Number of main indicators	Number of Indicators for which the State is in the Top 5 States	Top Quartile	2nd Quartile	3rd Quartile	Bottom Quartile	Bottom 5 States
50	Alabama	25	0	2	5	5	13	7
17	Alaska	19	9	12	1	2	4	3
15	Arizona	22	2	2	9	7	4	0
37	Arkansas	25	0	5	6	5	9	4
15	California	25	4	10	3	4	8	2
7	Colorado	25	2	7	10	8	0	0
11	Connecticut	24	2	6	9	6	3	1
32	Delaware	25	1	6	5	8	6	4
10	District of Columbia	20	6	11	2	3	4	4
44	Florida	25	1	6	2	6	11	2
42	Georgia	24	0	3	7	9	5	2
4	Hawaii	24	6	12	2	8	2	0
19	Idaho	25	2	8	6	5	6	4
23	Illinois	25	3	7	5	7	6	3
47	Indiana	24	0	3	4	7	10	3
6	Iowa	25	4	10	6	5	4	1
9	Kansas	25	2	7	9	6	3	1
46	Kentucky	23	0	1	2	9	11	4
43	Louisiana	25	0	5	4	7	9	7
8	Maine	23	4	8	8	4	3	3
24	Maryland	25	1	4	11	5	5	0
30	Massachusetts	25	2	4	11	6	4	0
31	Michigan	25	1	4	9	8	4	1
1	Minnesota	25	11	15	6	3	1	1
51	Mississippi	25	0	3	1	5	16	10
13	Missouri	25	2	5	9	8	3	1
33	Montana	24	1	7	6	5	6	3
14	Nebraska	25	4	7	6	9	3	1
40	Nevada	25	1	3	7	7	8	3
27	New Hampshire	25	3	5	8	8	4	1
22	New Jersey	25	1	7	3	9	6	2
26	New Mexico	24	3	6	10	6	2	0
41	New York	24	2	5	5	6	8	4
24	North Carolina	25	1	7	3	11	4	1
18	North Dakota	24	5	11	4	4	5	3
35	Ohio	25	0	2	9	9	5	2
48	Oklahoma	25	0	1	4	6	14	6
3	Oregon	25	9	13	4	6	2	0
39	Pennsylvania	24	2	3	8	7	6	0
34	Rhode Island	25	3	8	5	5	7	6
38	South Carolina	25	3	3	8	6	8	1
29	South Dakota	25	3	5	9	3	8	4
45	Tennessee	25	0	2	3	7	13	5
28	Texas	25	0	6	5	7	7	2
36	Utah	25	5	8	4	6	7	6
20	Vermont	25	3	9	5	5	6	0
12	Virginia	23	1	6	6	9	2	0
2	Washington	25	7	12	9	2	2	1
49	West Virginia	25	0	1	7	6	11	7
5	Wisconsin	25	1	10	9	2	4	0
20	Wyoming	25	3	7	7	6	5	2

* Final rank for overall state long-term services and supports performance across four dimensions.
Source: State Long-Term Services and Supports Scorecard, 2011.

Affordability and Access: Dimension and Indicator Ranking



Notes: PWD = People With Disabilities; ADRC/SEP = Aging and Disability Resource Center/Single Entry Point.
Source: State Long-Term Services and Supports Scorecard, 2011.

Affordability and Access: Indicator Performance and Ranking

	Median Annual Nursing Home Private Pay Cost as a Percentage of Median Household Income Age 65+		Median Annual Home Care Private Pay Cost as a Percentage of Median Household Income Age 65+		Private Long-Term Care Insurance Policies in Effect per 1,000 Population Age 40+	
State	**2010**	**Rank**	**2010**	**Rank**	**2009**	**Rank**
United States	**241%**		**88%**		**44**	
Alabama	215%	17	79%	7	33	43
Alaska	444%	51	95%	35	29	47
Arizona	224%	26	89%	25	35	38
Arkansas	201%	10	91%	29	29	47
California	224%	26	82%	10	43	24
Colorado	216%	19	89%	25	52	14
Connecticut	345%	48	83%	12	52	14
Delaware	277%	41	87%	18	40	29
District of Columbia	166%	1	55%	1	114	3
Florida	254%	37	82%	10	34	41
Georgia	188%	8	86%	17	34	41
Hawaii	236%	32	73%	4	121	2
Idaho	231%	30	87%	18	36	33
Illinois	203%	11	93%	30	45	22
Indiana	230%	29	94%	33	31	45
Iowa	179%	5	109%	47	87	7
Kansas	177%	4	87%	18	73	8
Kentucky	250%	35	94%	33	32	44
Louisiana	180%	6	84%	13	28	50
Maine	339%	47	120%	50	300	1
Maryland	207%	14	70%	2	56	11
Massachusetts	329%	46	108%	46	47	19
Michigan	249%	34	89%	25	36	33
Minnesota	219%	21	110%	48	71	9
Mississippi	267%	39	96%	37	31	45
Missouri	167%	3	87%	18	54	13
Montana	226%	28	98%	42	55	12
Nebraska	217%	20	96%	37	103	6
Nevada	215%	17	85%	16	29	47
New Hampshire	297%	42	107%	45	46	20
New Jersey	300%	44	81%	8	41	26
New Mexico	219%	21	77%	6	37	31
New York	393%	50	96%	37	35	38
North Carolina	221%	23	88%	23	41	26
North Dakota	233%	31	113%	49	107	5
Ohio	237%	33	88%	23	36	33
Oklahoma	181%	7	93%	30	35	38
Oregon	252%	36	95%	35	44	23
Pennsylvania	299%	43	97%	40	37	31
Rhode Island	350%	49	125%	51	38	30
South Carolina	211%	15	84%	13	42	25
South Dakota	223%	25	100%	43	110	4
Tennessee	212%	16	90%	28	41	26
Texas	205%	13	81%	8	36	33
Utah	166%	1	84%	13	36	33
Vermont	270%	40	97%	40	50	17
Virginia	196%	9	70%	2	63	10
Washington	221%	23	93%	30	48	18
West Virginia	306%	45	87%	18	28	50
Wisconsin	258%	38	101%	44	52	14
Wyoming	203%	11	75%	5	46	20

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Exhibit A3 (continued)

Affordability and Access: Indicator Performance and Ranking

State	Percent of Adults Age 21+ with ADL Disability at or Below 250% of Poverty Receiving Medicaid or Other Government Assistance Health Insurance		Medicaid LTSS Participant Years per 100 Adults Age 21+ with ADL Disability in Nursing Homes or at/below 250% in the Community		ADRC/Single Entry Point Functionality (Composite Indicator, scale 0–12)	
	2008–09	Rank	2007	Rank	2010	Rank
United States	**51.6%**		**36.9**			
Alabama	47.3%	39	21.9	44	4.2	46
Alaska	61.5%	4	46.8	9	3.6	47
Arizona	45.6%	45	*	*	8.2	23
Arkansas	49.2%	31	30.0	30	8.4	19
California	58.4%	6	69.9	2	5.1	42
Colorado	48.1%	37	37.2	22	7.7	26
Connecticut	57.0%	8	54.9	4	7.5	27
Delaware	47.0%	40	31.6	27	9.6	7
District of Columbia	60.8%	5	48.2	8	7.3	29
Florida	44.6%	46	24.1	40	10.9	2
Georgia	48.0%	38	20.5	45	8.1	24
Hawaii	51.8%	19	29.5	31	5.3	41
Idaho	44.3%	47	40.3	17	1.0	51
Illinois	48.3%	35	51.2	7	9.0	13
Indiana	48.8%	32	22.4	43	8.4	19
Iowa	49.8%	27	38.3	21	4.7	44
Kansas	46.9%	41	43.1	14	7.1	30
Kentucky	50.2%	25	*	*	5.8	38
Louisiana	54.2%	11	25.3	36	8.4	19
Maine	63.6%	1	*	*	6.8	31
Maryland	51.1%	23	31.9	26	8.9	14
Massachusetts	61.8%	3	38.7	20	10.7	3
Michigan	51.7%	20	24.5	38	6.5	32
Minnesota	53.9%	12	74.6	1	11.0	1
Mississippi	54.6%	10	24.8	37	6.3	34
Missouri	51.7%	20	45.9	10	6.1	36
Montana	41.5%	48	30.2	29	8.0	25
Nebraska	48.5%	33	31.2	28	5.1	42
Nevada	39.9%	50	26.7	35	7.4	28
New Hampshire	52.3%	17	40.5	16	9.4	10
New Jersey	52.6%	15	43.2	13	9.4	10
New Mexico	50.4%	24	37.0	23	8.7	16
New York	63.1%	2	51.8	6	8.4	19
North Carolina	49.4%	28	45.7	11	9.7	6
North Dakota	53.6%	13	34.1	25	4.3	45
Ohio	51.2%	22	36.1	24	6.0	37
Oklahoma	46.7%	42	39.3	18	2.5	49
Oregon	46.0%	43	42.1	15	10.1	4
Pennsylvania	48.5%	33	26.8	34	8.9	14
Rhode Island	56.8%	9	39.1	19	6.2	35
South Carolina	49.3%	29	23.6	41	9.8	5
South Dakota	45.7%	44	28.1	33	8.7	16
Tennessee	48.2%	36	15.9	47	5.4	40
Texas	49.3%	29	23.4	42	8.7	16
Utah	38.7%	51	17.3	46	3.2	48
Vermont	58.2%	7	63.3	3	6.5	32
Virginia	52.4%	16	*	*	5.5	39
Washington	52.1%	18	54.5	5	9.6	7
West Virginia	49.9%	26	24.2	39	9.3	12
Wisconsin	52.9%	14	43.6	12	9.6	7
Wyoming	40.7%	49	29.1	32	1.3	50

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Income, Private Pay Cost, and LTSS Affordability

State	Median Household Income Age 65+	Median Annual Cost of Care: Nursing Home Private Room	Median Annual Cost of Care: 30 Hours/Week of Home Care	Median Cost as a Percentage of Median Household Income*: Nursing Home Private Room	Median Cost as a Percentage of Median Household Income*: 30 Hours/Week of Home Care
United States	$33,712	$75,190	$29,640	241%	88%
Alabama	$29,107	$63,875	$23,400	215%	79%
Alaska	$47,296	$202,210	$39,000	444%	95%
Arizona	$36,855	$79,840	$31,200	224%	89%
Arkansas	$27,422	$56,575	$25,740	201%	91%
California	$39,891	$87,345	$31,980	224%	82%
Colorado	$37,284	$79,570	$33,119	216%	89%
Connecticut	$39,582	$137,058	$33,540	345%	83%
Delaware	$38,240	$89,060	$32,760	277%	87%
District of Columbia	$42,495	$94,243	$31,200	166%	55%
Florida	$34,214	$82,125	$28,439	254%	82%
Georgia	$31,107	$61,926	$26,520	188%	86%
Hawaii	$50,784	$114,975	$35,100	236%	73%
Idaho	$32,084	$75,190	$26,520	231%	87%
Illinois	$34,261	$63,601	$31,200	203%	93%
Indiana	$31,505	$75,606	$29,640	230%	94%
Iowa	$31,863	$56,393	$31,949	179%	109%
Kansas	$32,368	$56,575	$28,283	177%	87%
Kentucky	$27,078	$69,350	$26,520	250%	94%
Louisiana	$28,485	$51,056	$24,180	180%	84%
Maine	$29,518	$101,302	$35,880	339%	120%
Maryland	$44,486	$83,585	$31,200	207%	70%
Massachusetts	$34,764	$116,983	$37,440	329%	108%
Michigan	$32,668	$82,125	$29,453	249%	89%
Minnesota	$34,000	$74,460	$39,000	219%	110%
Mississippi	$24,999	$68,010	$24,960	267%	96%
Missouri	$31,586	$51,191	$28,080	167%	87%
Montana	$30,964	$67,832	$30,701	226%	98%
Nebraska	$32,248	$66,613	$29,640	217%	96%
Nevada	$37,015	$76,833	$32,370	215%	85%
New Hampshire	$36,548	$98,185	$36,660	297%	107%
New Jersey	$39,553	$109,865	$31,918	300%	81%
New Mexico	$32,831	$71,686	$29,250	219%	77%
New York	$33,882	$116,800	$33,150	393%	96%
North Carolina	$31,064	$71,175	$28,080	221%	88%
North Dakota	$29,853	$74,095	$34,242	233%	113%
Ohio	$31,380	$74,825	$28,860	237%	88%
Oklahoma	$31,028	$52,104	$28,439	181%	93%
Oregon	$33,865	$83,950	$31,980	252%	95%
Pennsylvania	$30,937	$90,338	$30,420	299%	97%
Rhode Island	$32,520	$100,740	$39,000	350%	125%
South Carolina	$32,150	$68,054	$26,567	211%	84%
South Dakota	$30,138	$67,525	$29,640	223%	100%
Tennessee	$29,495	$64,058	$27,300	212%	90%
Texas	$33,613	$58,765	$28,002	205%	81%
Utah	$39,569	$63,875	$32,760	166%	84%
Vermont	$33,076	$88,330	$32,760	270%	97%
Virginia	$38,920	$73,000	$28,080	196%	70%
Washington	$39,249	$86,461	$33,883	221%	93%
West Virginia	$25,984	$84,571	$22,620	306%	87%
Wisconsin	$32,172	$82,125	$33,353	258%	101%
Wyoming	$34,343	$72,818	$25,740	203%	75%

* These ratios are calculated at the market, not state, level and may not be exactly equal to the ratio of state median cost to state median income.
Data: 2010 Genworth Cost of Care Survey; 2009 American Community Survey; 2009 American Community Survey Public Use Microdata Sample.
Source: State Long-Term Services and Supports Scorecard, 2011.

ADRC/Single Entry Point Functionality: Composite Indicator Rank and Component Scores

	Private Pay, Target Population and Partnership	Continuous Quality Improvement	Formal Marketing	Information and Referral/ Assistance	Options Counseling	Overall Coordination and Tracking Eligibility
Alabama	0.58	0.40	0.50	0.78	0.33	0.25
Alaska	0.75	0.50	0.50	0.71	0.38	0.00
Arizona	0.92	0.50	1.00	0.78	0.67	0.75
Arkansas	0.92	0.60	1.00	0.86	0.75	0.75
California	0.50	0.40	0.50	0.43	0.50	0.25
Colorado	0.83	0.50	0.50	0.56	0.44	0.25
Connecticut	0.75	0.50	0.50	0.89	0.89	0.25
Delaware	0.92	0.60	1.00	0.89	0.44	1.00
District of Columbia	1.00	0.60	1.00	0.86	0.63	0.50
Florida	0.83	1.00	0.50	0.89	0.89	1.00
Georgia	0.83	0.90	1.00	0.86	0.75	0.25
Hawaii	0.67	0.50	1.00	0.43	0.25	0.75
Idaho	0.25	0.10	0.00	0.29	0.13	0.00
Illinois	0.75	0.70	0.50	0.67	0.56	0.75
Indiana	0.75	0.70	0.50	0.57	0.38	1.00
Iowa	0.75	0.60	0.50	0.57	0.50	0.00
Kansas	0.67	0.30	0.00	0.78	0.25	0.50
Kentucky	0.83	0.40	0.50	0.71	0.63	0.25
Louisiana	0.75	0.30	1.00	0.67	0.38	1.00
Maine	0.67	0.80	0.50	0.33	0.63	0.50
Maryland	0.83	0.50	1.00	0.67	0.78	0.50
Massachusetts	0.92	0.60	1.00	0.78	0.89	1.00
Michigan	0.92	0.80	0.50	0.67	0.56	0.25
Minnesota	1.00	1.00	1.00	0.89	0.78	0.75
Mississippi	0.50	0.40	0.50	0.86	0.50	0.50
Missouri	0.92	0.20	1.00	0.71	0.75	0.50
Montana	0.67	0.40	0.50	1.00	0.56	0.25
Nebraska	0.67	0.20	0.50	0.57	0.13	0.25
Nevada	0.83	0.70	1.00	0.67	0.56	0.50
New Hampshire	0.92	1.00	1.00	0.89	1.00	1.00
New Jersey	0.92	0.90	1.00	0.78	0.78	1.00
New Mexico	0.92	0.80	1.00	1.00	1.00	1.00
New York	0.92	0.60	1.00	0.71	0.63	1.00
North Carolina	0.83	0.60	1.00	0.89	0.33	0.75
North Dakota	0.58	0.40	0.50	0.86	1.00	0.00
Ohio	0.42	0.00	0.00	0.33	0.22	0.50
Oklahoma	0.58	0.20	0.50	0.57	0.38	0.00
Oregon	0.75	0.60	0.50	0.89	0.56	1.00
Pennsylvania	0.75	0.20	0.50	0.67	0.44	1.00
Rhode Island	0.75	0.70	0.50	0.89	0.67	0.50
South Carolina	0.75	0.50	0.50	1.00	0.89	1.00
South Dakota	0.67	0.70	1.00	0.67	0.56	0.50
Tennessee	0.75	0.40	1.00	0.71	0.50	0.50
Texas	0.67	0.40	0.50	0.78	0.33	0.50
Utah	0.50	0.40	0.00	0.43	0.38	0.00
Vermont	0.75	0.50	0.50	0.78	0.56	1.00
Virginia	0.75	0.30	0.50	0.71	0.25	0.25
Washington	0.83	0.70	0.50	0.89	0.67	1.00
West Virginia	0.75	0.70	1.00	0.71	0.63	1.00
Wisconsin	1.00	1.00	1.00	0.71	0.88	1.00
Wyoming	0.17	0.00	0.00	0.22	0.11	0.00

Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

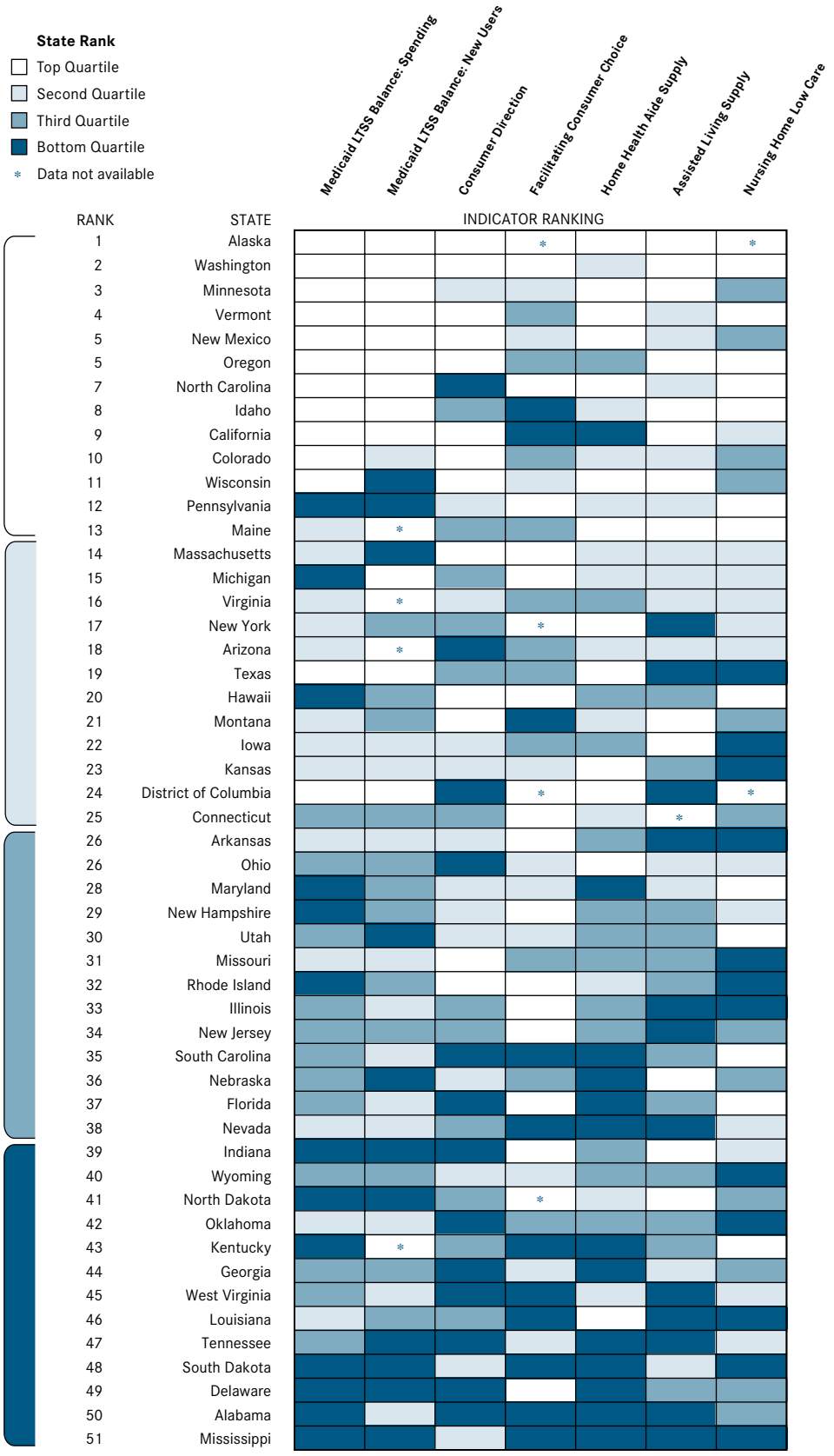
Exhibit A5 (continued)

ADRC/Single Entry Point Functionality: Composite Indicator Rank and Component Scores

	Screening	Nursing Facility Pre-Admission Screening	Financial Eligibility Determiniation	Level of Care/ Functional Eligibility Determination	Service Planning and Delivery	Transition Services	Overall Score	Rank
Alabama	0.33	0.00	0.00	0.60	0.00	0.40	4.2	46
Alaska	0.00	0.00	0.00	0.00	0.00	0.75	3.6	47
Arizona	1.00	0.00	0.67	0.70	1.00	0.20	8.2	23
Arkansas	1.00	0.00	0.50	1.00	0.00	1.00	8.4	19
California	0.50	0.00	0.50	0.50	0.00	1.00	5.1	42
Colorado	0.33	1.00	1.00	0.90	1.00	0.40	7.7	26
Connecticut	0.67	0.00	0.33	0.90	1.00	0.80	7.5	27
Delaware	1.00	0.00	1.00	0.90	1.00	0.80	9.6	7
District of Columbia	0.50	0.00	0.50	1.00	0.00	0.75	7.3	29
Florida	1.00	1.00	1.00	1.00	1.00	0.80	10.9	2
Georgia	1.00	0.00	0.50	1.00	0.00	1.00	8.1	24
Hawaii	0.50	0.00	0.50	0.50	0.00	0.25	5.3	41
Idaho	0.00	0.00	0.00	0.00	0.00	0.25	1.0	51
Illinois	1.00	1.00	1.00	0.90	1.00	0.20	9.0	13
Indiana	1.00	1.00	1.00	1.00	0.00	0.50	8.4	19
Iowa	0.50	0.00	0.50	0.00	0.00	0.75	4.7	44
Kansas	1.00	1.00	0.67	0.90	0.67	0.40	7.1	30
Kentucky	0.50	0.00	0.50	1.00	0.00	0.50	5.8	38
Louisiana	1.00	1.00	0.67	1.00	0.67	0.00	8.4	19
Maine	0.67	1.00	0.33	1.00	0.00	0.40	6.8	31
Maryland	0.67	0.00	1.00	1.00	1.00	1.00	8.9	14
Massachusetts	1.00	1.00	1.00	0.90	1.00	0.60	10.7	3
Michigan	1.00	0.00	0.67	0.50	0.00	0.60	6.5	32
Minnesota	1.00	1.00	1.00	1.00	1.00	0.60	11.0	1
Mississippi	1.00	0.00	1.00	1.00	0.00	0.00	6.3	34
Missouri	0.00	0.00	0.50	1.00	0.00	0.50	6.1	36
Montana	1.00	1.00	1.00	0.90	0.33	0.40	8.0	25
Nebraska	1.00	0.00	0.50	1.00	0.00	0.25	5.1	42
Nevada	0.67	0.00	0.67	0.80	1.00	0.00	7.4	28
New Hampshire	1.00	0.00	1.00	1.00	0.00	0.60	9.4	10
New Jersey	1.00	0.00	0.67	0.60	1.00	0.80	9.4	10
New Mexico	1.00	0.00	0.50	1.00	0.00	0.50	8.7	16
New York	1.00	0.00	1.00	1.00	0.00	0.50	8.4	19
North Carolina	1.00	1.00	0.67	1.00	1.00	0.60	9.7	6
North Dakota	0.50	0.00	0.00	0.00	0.00	0.50	4.3	45
Ohio	0.67	1.00	0.67	0.80	1.00	0.40	6.0	37
Oklahoma	0.00	0.00	0.00	0.00	0.00	0.25	2.5	49
Oregon	1.00	1.00	1.00	1.00	1.00	0.80	10.1	4
Pennsylvania	1.00	1.00	1.00	0.90	1.00	0.40	8.9	14
Rhode Island	0.67	0.00	0.67	0.50	0.00	0.40	6.2	35
South Carolina	1.00	1.00	1.00	1.00	1.00	0.17	9.8	5
South Dakota	0.33	1.00	0.67	1.00	1.00	0.60	8.7	16
Tennessee	0.50	0.00	0.00	0.50	0.00	0.50	5.4	40
Texas	1.00	1.00	1.00	0.70	1.00	0.80	8.7	16
Utah	0.00	0.00	0.00	1.00	0.00	0.50	3.2	48
Vermont	0.67	0.00	0.67	0.70	0.00	0.40	6.5	32
Virginia	0.00	1.00	1.00	0.50	0.00	0.25	5.5	39
Washington	1.00	0.00	1.00	1.00	1.00	1.00	9.6	7
West Virginia	1.00	1.00	1.00	0.50	0.00	1.00	9.3	12
Wisconsin	1.00	0.00	1.00	1.00	0.00	1.00	9.6	7
Wyoming	0.33	0.00	0.33	0.10	0.00	0.00	1.3	50

Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Choice of Setting and Provider: Dimension and Indicator Ranking



Source: State Long-Term Services and Supports Scorecard, 2011.

Choice of Setting and Provider: Indicator Performance and Ranking

	Percent of Medicaid and State-Funded LTSS Spending for Older People and Adults with Physical Disabilities Going to HCBS		Percent of New Medicaid LTSS Users First Receiving Services in the Community		Number of People Consumer-Directing Services per 1,000 Age 18+ with Disabilities	
	2009	Rank	2007	Rank	2010	Rank
United States	**36.8%**		**57.2%**		**22.3**	
Alabama	14.9%	47	50.8%	22	0.1	49
Alaska	56.4%	5	75.0%	3	51.2	4
Arizona	41.5%	15	*	*	3.1	39
Arkansas	29.7%	26	62.9%	14	10.8	22
California	53.7%	6	70.9%	5	142.7	1
Colorado	44.8%	10	59.1%	16	44.7	5
Connecticut	27.4%	31	38.3%	30	7.3	28
Delaware	13.2%	50	28.8%	44	0.3	48
District of Columbia	45.6%	9	67.2%	10	0.02	51
Florida	22.0%	38	49.9%	24	0.9	46
Georgia	26.8%	33	32.7%	36	2.8	41
Hawaii	20.5%	42	37.0%	33	18.3	10
Idaho	43.8%	11	67.5%	8	7	30
Illinois	27.9%	29	64.6%	13	7.1	29
Indiana	18.0%	44	21.8%	47	1.2	45
Iowa	30.3%	24	58.7%	17	10.1	24
Kansas	40.1%	17	55.6%	18	11.1	21
Kentucky	21.9%	39	*	*	6.6	31
Louisiana	32.5%	23	40.5%	28	3.9	36
Maine	30.1%	25	*	*	4.8	35
Maryland	15.8%	45	37.2%	31	13.9	14
Massachusetts	38.9%	18	31.0%	40	29.3	8
Michigan	21.5%	41	82.8%	2	7.8	27
Minnesota	60.0%	3	83.3%	1	12.2	20
Mississippi	15.8%	45	32.5%	37	8.9	25
Missouri	35.0%	20	54.2%	20	20.1	9
Montana	33.9%	21	39.9%	29	40.7	6
Nebraska	25.2%	36	31.6%	38	13.4	15
Nevada	40.8%	16	55.5%	19	5.1	34
New Hampshire	20.3%	43	36.3%	35	12.8	17
New Jersey	28.7%	28	49.4%	26	3.3	37
New Mexico	63.9%	1	73.7%	4	17.4	11
New York	41.7%	14	48.8%	27	5.2	33
North Carolina	43.8%	11	67.3%	9	0.1	49
North Dakota	10.5%	51	31.1%	39	6.4	32
Ohio	24.3%	37	37.1%	32	0.8	47
Oklahoma	32.6%	22	60.1%	15	1.8	43
Oregon	56.6%	4	69.7%	6	52.2	3
Pennsylvania	21.9%	39	31.0%	40	12.8	17
Rhode Island	14.4%	48	36.5%	34	14.2	13
South Carolina	27.9%	29	50.6%	23	3.1	39
South Dakota	14.0%	49	24.9%	45	12.5	19
Tennessee	26.2%	34	22.8%	46	1.4	44
Texas	50.8%	7	67.6%	7	3.2	38
Utah	29.1%	27	29.5%	43	13.2	16
Vermont	45.8%	8	65.1%	12	56.2	2
Virginia	36.1%	19	*	*	10.2	23
Washington	62.7%	2	66.5%	11	30.8	7
West Virginia	27.0%	32	52.5%	21	2.2	42
Wisconsin	43.5%	13	29.8%	42	17.4	11
Wyoming	25.8%	35	49.7%	25	8	26

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Exhibit A7 (continued)

Choice of Setting and Provider: Indicator Performance and Ranking

	Tools and Programs to Facilitate Consumer Choice (Composite Indicator, scale 0–4)		Home Health and Personal Care Aides per 1,000 Population Age 65+		Assisted Living and Residential Care Units per 1,000 Population Age 65+		Percent of Nursing Home Residents With Low Care Needs	
	2010	Rank	2009	Rank	2010	Rank	2007	Rank
United States			**40**		**31**		**12.8%**	
Alabama	1.00	41	20	45	15	44	14.9%	34
Alaska	*	*	71	6	55	5	*	*
Arizona	2.57	29	37	21	33	18	11.2%	21
Arkansas	3.50	6	30	33	19	40	17.4%	41
California	0.67	45	23	42	51	7	10.8%	19
Colorado	2.60	26	36	23	31	19	12.9%	27
Connecticut	3.00	10	42	16	*	*	15.5%	35
Delaware	3.00	10	19	47	22	37	13.5%	29
District of Columbia	*	*	56	8	7	50	*	*
Florida	3.19	9	14	49	26	30	8.1%	10
Georgia	2.75	22	20	45	30	22	12.7%	26
Hawaii	3.00	10	28	38	26	30	6.0%	2
Idaho	1.00	41	37	21	62	3	7.8%	7
Illinois	4.00	1	30	33	14	45	25.1%	49
Indiana	3.00	10	32	29	40	12	11.7%	24
Iowa	2.60	26	34	26	48	8	17.5%	42
Kansas	2.75	22	54	10	23	36	18.6%	45
Kentucky	1.80	39	13	51	27	27	7.4%	6
Louisiana	1.83	38	48	12	11	48	22.6%	47
Maine	1.90	36	56	8	44	11	1.3%	1
Maryland	2.83	17	22	43	29	25	8.0%	9
Massachusetts	3.00	10	38	20	29	25	10.1%	17
Michigan	3.40	7	36	23	30	22	10.4%	18
Minnesota	2.90	16	108	1	80	1	14.5%	32
Mississippi	1.00	41	14	49	13	47	17.5%	42
Missouri	2.00	34	34	26	26	30	20.0%	46
Montana	0.67	45	41	17	37	13	16.3%	37
Nebraska	2.40	30	18	48	47	9	13.6%	30
Nevada	1.86	37	27	39	14	45	10.9%	20
New Hampshire	3.57	5	30	33	27	27	11.6%	23
New Jersey	3.67	4	30	33	17	42	13.9%	31
New Mexico	2.80	19	84	3	30	22	13.3%	28
New York	*	*	87	2	16	43	11.4%	22
North Carolina	3.00	10	75	5	36	14	8.1%	10
North Dakota	*	*	36	23	46	10	16.1%	36
Ohio	2.80	19	46	13	31	19	9.1%	15
Oklahoma	2.00	34	34	26	25	33	24.4%	48
Oregon	2.20	33	32	29	64	2	8.3%	13
Pennsylvania	4.00	1	43	14	36	14	6.7%	4
Rhode Island	3.33	8	43	14	25	33	17.7%	44
South Carolina	1.42	40	25	41	27	27	6.5%	3
South Dakota	0.50	47	22	43	34	16	17.0%	39
Tennessee	2.67	25	27	39	18	41	10.0%	16
Texas	2.27	32	71	6	20	39	16.4%	38
Utah	2.80	19	30	33	24	35	8.1%	10
Vermont	2.40	30	84	3	31	19	7.9%	8
Virginia	2.60	26	31	32	34	16	8.6%	14
Washington	3.70	3	41	17	55	5	6.7%	4
West Virginia	1.00	41	39	19	11	48	11.9%	25
Wisconsin	2.83	17	51	11	59	4	14.8%	33
Wyoming	2.75	22	32	29	22	37	17.0%	39

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Tools and Programs to Facilitate Consumer Choice: Composite Indicator Rank and Component Scores

State	Tools		Programs			
	Presumptive Eligibility	Uniform Assessment	Money Follows the Person/Nursing Home Transition	Options Counseling	Overall Score	Rank
Alabama	0.00	1.00	0.00	0.00	1.00	41
Alaska	*	*	*	*	*	*
Arizona	0.00	1.00	0.67	0.90	2.57	29
Arkansas	1.00	0.50	1.00	1.00	3.50	6
California	0.00	0.00	0.67	0.00	0.67	45
Colorado	0.00	1.00	1.00	0.60	2.60	26
Connecticut	0.00	1.00	1.00	1.00	3.00	10
Delaware	0.00	1.00	1.00	1.00	3.00	10
District of Columbia	*	*	*	*	*	*
Florida	1.00	0.86	0.33	1.00	3.19	9
Georgia	0.00	0.75	1.00	1.00	2.75	22
Hawaii	0.00	1.00	1.00	1.00	3.00	10
Idaho	0.00	1.00	0.00	0.00	1.00	41
Illinois	1.00	1.00	1.00	1.00	4.00	1
Indiana	0.00	1.00	1.00	1.00	3.00	10
Iowa	0.00	0.60	1.00	1.00	2.60	26
Kansas	1.00	0.75	1.00	0.00	2.75	22
Kentucky	0.00	0.80	1.00	0.00	1.80	39
Louisiana	0.00	0.83	1.00	0.00	1.83	38
Maine	0.00	1.00	0.00	0.90	1.90	36
Maryland	0.00	0.83	1.00	1.00	2.83	17
Massachusetts	0.00	1.00	1.00	1.00	3.00	10
Michigan	1.00	1.00	1.00	0.40	3.40	7
Minnesota	0.00	1.00	1.00	0.90	2.90	16
Mississippi	0.00	0.00	0.00	1.00	1.00	41
Missouri	0.00	1.00	1.00	0.00	2.00	34
Montana	0.00	0.00	0.67	0.00	0.67	45
Nebraska	0.00	1.00	1.00	0.40	2.40	30
Nevada	0.00	0.86	0.00	1.00	1.86	37
New Hampshire	1.00	0.67	1.00	0.90	3.57	5
New Jersey	1.00	1.00	0.67	1.00	3.67	4
New Mexico	0.00	0.80	1.00	1.00	2.80	19
New York	*	*	*	*	*	*
North Carolina	0.00	1.00	1.00	1.00	3.00	10
North Dakota	*	*	*	*	*	*
Ohio	1.00	0.00	1.00	0.80	2.80	19
Oklahoma	0.00	1.00	1.00	0.00	2.00	34
Oregon	0.00	0.80	1.00	0.40	2.20	33
Pennsylvania	1.00	1.00	1.00	1.00	4.00	1
Rhode Island	1.00	0.33	1.00	1.00	3.33	8
South Carolina	0.00	0.75	0.67	0.00	1.42	40
South Dakota	0.00	0.50	0.00	0.00	0.50	47
Tennessee	1.00	0.67	0.00	1.00	2.67	25
Texas	0.00	0.60	0.67	1.00	2.27	32
Utah	0.00	0.80	1.00	1.00	2.80	19
Vermont	0.00	1.00	1.00	0.40	2.40	30
Virginia	0.00	1.00	1.00	0.60	2.60	26
Washington	1.00	1.00	1.00	0.70	3.70	3
West Virginia	0.00	0.00	1.00	0.00	1.00	41
Wisconsin	0.83	0.00	1.00	1.00	2.83	17
Wyoming	1.00	0.75	1.00	0.00	2.75	22

* AK, DC, NY, and ND did not respond to the AARP state survey and therefore data were not available for this indicator.
Data: See Appendix B2 for a full description of this indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Quality of Life and Quality of Care: Dimension and Indicator Ranking

Note: PWD = People With Disabilities.
Source: State Long-Term Services and Supports Scorecard, 2011.

Quality of Life and Quality of Care: Indicator Performance and Ranking

	Percent of Adults Age 18+ with Disabilities in the Community Usually or Always Getting Needed Support		Percent of Adults Age 18+ with Disabilities in the Community Satisfied or Very Satisfied with Life		Rate of Employment for Adults with ADL Disability Age 18-64 Relative to Rate of Employment for Adults without ADL Disability Age 18-64		Percent of High Risk Nursing Home Residents with Pressure Sores	
	2009	Rank	2009	Rank	2008-09	Rank	2008	Rank
United States	**68.0%**		**84.4%**		**24.3%**		**11.6%**	
Alabama	65.8%	44	85.0%	25	18.3%	50	9.4%	11
Alaska	78.2%	1	91.5%	2	39.2%	3	*	*
Arizona	71.3%	17	83.7%	36	21.0%	43	10.9%	24
Arkansas	66.4%	40	87.6%	8	22.6%	37	10.8%	22
California	67.1%	35	83.2%	43	22.2%	39	12.7%	40
Colorado	72.3%	11	84.9%	28	27.5%	17	8.9%	10
Connecticut	70.9%	18	85.4%	23	29.0%	11	9.6%	14
Delaware	72.3%	11	87.2%	11	24.0%	29	10.6%	19
District of Columbia	62.3%	49	86.3%	18	23.0%	35	16.2%	49
Florida	67.7%	32	83.2%	43	23.8%	30	12.3%	39
Georgia	66.7%	39	87.4%	9	22.3%	38	11.8%	34
Hawaii	68.1%	31	90.4%	4	23.5%	31	8.2%	6
Idaho	70.2%	22	85.4%	23	21.7%	42	8.7%	9
Illinois	68.5%	25	87.0%	14	26.0%	21	14.6%	46
Indiana	68.4%	27	87.2%	11	22.2%	39	11.7%	33
Iowa	72.5%	10	87.4%	9	34.5%	8	7.8%	5
Kansas	73.8%	7	88.3%	7	23.3%	33	9.5%	13
Kentucky	65.6%	45	82.2%	48	18.8%	49	11.5%	31
Louisiana	68.4%	27	84.0%	35	23.3%	33	17.2%	50
Maine	69.8%	23	86.8%	16	24.1%	27	8.2%	6
Maryland	68.5%	25	82.9%	45	27.6%	15	13.3%	44
Massachusetts	68.4%	27	83.5%	38	24.3%	25	10.0%	16
Michigan	71.9%	13	83.5%	38	20.2%	44	10.1%	17
Minnesota	73.9%	5	86.3%	18	36.0%	5	6.6%	1
Mississippi	61.3%	51	84.4%	34	19.0%	48	12.0%	37
Missouri	70.4%	19	85.0%	25	23.5%	31	11.5%	31
Montana	70.3%	21	84.7%	30	41.1%	2	8.5%	8
Nebraska	71.7%	16	89.1%	5	28.4%	12	7.4%	4
Nevada	70.4%	19	82.8%	46	36.0%	5	12.9%	42
New Hampshire	66.9%	37	85.0%	25	22.9%	36	7.1%	2
New Jersey	67.2%	34	83.4%	40	29.4%	10	15.6%	48
New Mexico	68.7%	24	84.6%	32	24.6%	23	11.9%	36
New York	62.2%	50	83.6%	37	24.2%	26	13.3%	44
North Carolina	65.4%	46	84.7%	30	21.8%	41	11.1%	25
North Dakota	71.9%	13	91.0%	3	56.6%	1	7.3%	3
Ohio	67.5%	33	82.5%	47	27.6%	15	11.1%	25
Oklahoma	67.1%	35	83.3%	42	24.6%	23	14.6%	46
Oregon	73.9%	5	86.1%	20	29.9%	9	10.8%	22
Pennsylvania	66.0%	42	83.4%	40	24.1%	27	11.1%	25
Rhode Island	64.4%	47	80.2%	51	35.8%	7	10.7%	21
South Carolina	66.9%	37	86.9%	15	17.6%	51	10.6%	19
South Dakota	76.2%	2	92.4%	1	26.6%	19	11.2%	28
Tennessee	64.0%	48	80.4%	50	19.9%	46	11.4%	30
Texas	66.1%	41	84.6%	32	26.5%	20	11.8%	34
Utah	74.4%	4	88.6%	6	27.1%	18	9.4%	11
Vermont	65.9%	43	86.4%	17	20.1%	45	10.5%	18
Virginia	72.8%	9	84.8%	29	25.3%	22	12.9%	42
Washington	72.9%	8	85.9%	21	28.1%	14	11.3%	29
West Virginia	68.3%	30	81.5%	49	19.3%	47	12.1%	38
Wisconsin	71.8%	15	85.6%	22	28.2%	13	9.6%	14
Wyoming	74.8%	3	87.2%	11	39.0%	4	12.7%	40

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

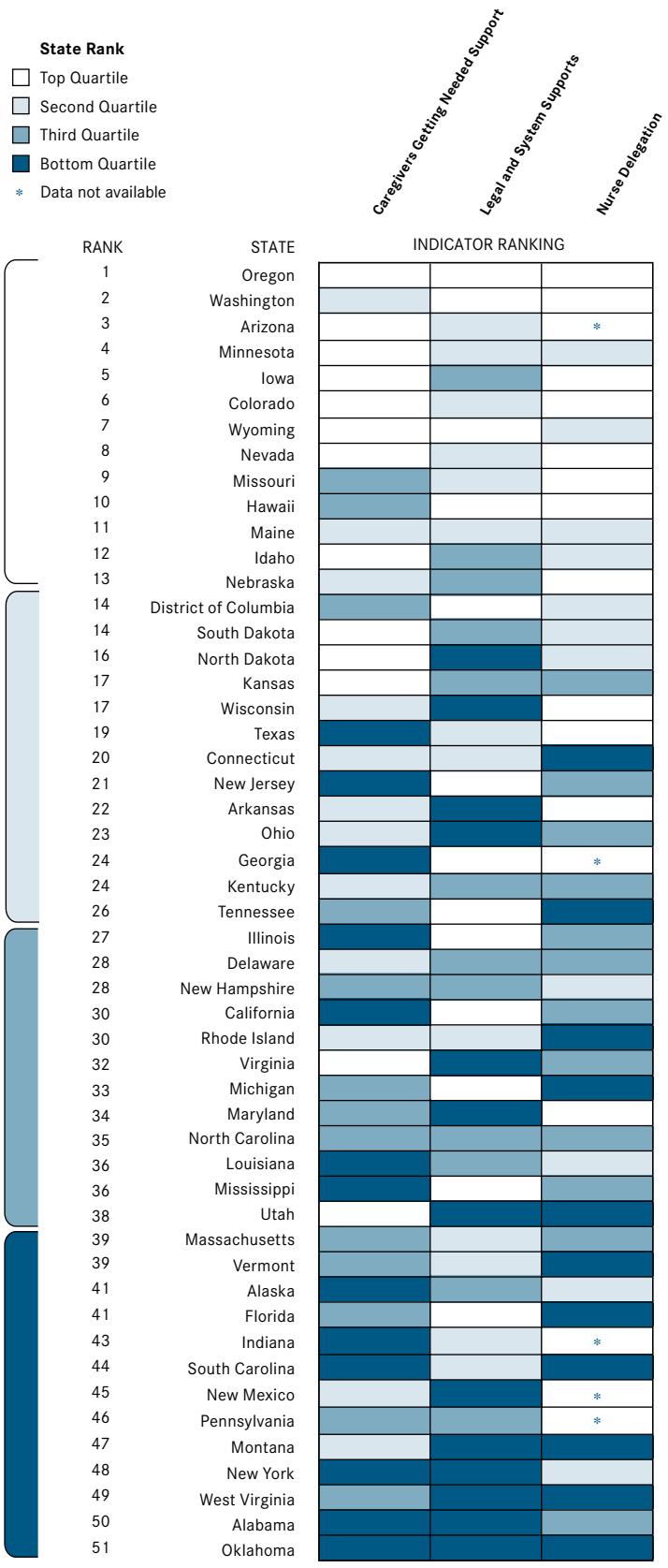
Exhibit A10 (continued)

Quality of Life and Quality of Care: Indicator Performance and Ranking

	Percent of Long-Stay Nursing Home Residents Who were Physically Restrained		Nursing Home Staffing Turnover: Ratio of Employee Terminations to the Average Number of Active Employees		Percent of Long-Stay Nursing Home Residents with a Hospital Admission		Percent of Home Health Episodes of Care in which Interventions to Prevent Pressure Sores were Included in the Plan of Care for At-Risk Patients		Percent of Home Health Patients with a Hospital Admission	
	2008	Rank	2008	Rank	2008	Rank	2010	Rank	2008	Rank
United States	**3.9%**		**48.7%**		**20.5%**		**90%**		**30.8%**	
Alabama	2.0%	13	47.3%	25	22.9%	38	91%	19	29.9%	31
Alaska	*	*	*	*	*	*	95%	3	25.1%	7
Arizona	3.3%	25	52.9%	30	10.8%	3	91%	19	30.6%	35
Arkansas	5.6%	42	72.4%	45	27.6%	46	94%	5	33.2%	42
California	7.9%	49	40.6%	17	20.4%	29	93%	8	26.2%	12
Colorado	4.4%	37	53.6%	31	12.1%	7	88%	35	27.7%	20
Connecticut	2.6%	18	18.7%	1	18.7%	23	89%	31	33.7%	45
Delaware	1.6%	8	42.3%	18	20.5%	31	96%	2	26.4%	14
District of Columbia	*	*	*	*	*	*	94%	5	23.3%	2
Florida	5.0%	39	45.4%	22	24.4%	40	86%	43	26.2%	12
Georgia	4.1%	33	45.2%	21	20.8%	33	92%	16	28.8%	25
Hawaii	2.0%	13	31.4%	5	*	*	97%	1	25.2%	9
Idaho	3.5%	27	72.4%	45	12.7%	8	85%	44	24.2%	5
Illinois	3.7%	28	27.2%	2	25.3%	43	93%	8	31.6%	39
Indiana	3.2%	24	76.9%	48	20.4%	29	87%	40	33.3%	43
Iowa	1.5%	5	38.2%	13	17.2%	19	90%	26	33.4%	44
Kansas	0.9%	1	63.2%	38	21.6%	35	91%	19	28.0%	22
Kentucky	5.2%	40	74.5%	47	24.1%	39	90%	26	32.7%	40
Louisiana	7.5%	48	33.9%	9	31.6%	47	93%	8	40.2%	51
Maine	1.4%	3	39.6%	16	16.6%	18	79%	50	25.7%	11
Maryland	2.8%	21	43.5%	19	20.7%	32	89%	31	27.3%	18
Massachusetts	4.2%	35	39.4%	15	16.5%	17	87%	40	31.4%	38
Michigan	3.9%	30	35.8%	10	18.8%	24	91%	19	26.7%	15
Minnesota	1.9%	11	36.8%	12	8.3%	1	88%	35	31.3%	37
Mississippi	6.0%	45	36.5%	11	32.5%	48	84%	48	36.3%	48
Missouri	4.0%	32	69.3%	42	22.3%	37	92%	16	26.7%	15
Montana	2.3%	17	*	*	13.4%	9	85%	44	25.6%	10
Nebraska	1.1%	2	47.8%	26	17.8%	20	88%	35	28.0%	22
Nevada	4.1%	33	69.3%	42	19.2%	26	90%	26	30.0%	32
New Hampshire	1.4%	3	38.6%	14	13.6%	11	82%	49	29.2%	28
New Jersey	3.8%	29	32.4%	7	26.5%	45	94%	5	28.1%	24
New Mexico	5.9%	44	60.0%	34	14.1%	12	91%	19	30.1%	33
New York	3.3%	25	32.2%	6	20.2%	28	93%	8	37.6%	50
North Carolina	3.9%	30	57.8%	33	18.9%	25	85%	44	29.4%	29
North Dakota	1.5%	5	33.6%	8	13.4%	9	92%	16	23.3%	2
Ohio	4.7%	38	60.0%	34	18.6%	22	93%	8	34.1%	46
Oklahoma	5.3%	41	64.4%	39	26.2%	44	88%	35	37.1%	49
Oregon	4.2%	35	49.3%	27	11.1%	4	85%	44	24.8%	6
Pennsylvania	2.6%	18	44.1%	20	17.9%	21	93%	8	27.3%	18
Rhode Island	1.6%	8	29.9%	4	11.6%	5	95%	3	30.8%	36
South Carolina	5.7%	43	28.8%	3	19.7%	27	91%	19	29.0%	26
South Dakota	2.0%	13	46.4%	24	15.8%	16	77%	51	25.1%	7
Tennessee	6.2%	46	57.5%	32	24.6%	41	93%	8	32.8%	41
Texas	2.9%	22	46.2%	23	25.0%	42	90%	26	35.2%	47
Utah	7.4%	47	51.9%	29	10.4%	2	89%	31	21.8%	1
Vermont	1.9%	11	69.1%	41	11.8%	6	88%	35	29.5%	30
Virginia	1.8%	10	49.6%	28	21.7%	36	90%	26	29.0%	26
Washington	2.1%	16	72.0%	44	14.4%	13	87%	40	23.6%	4
West Virginia	3.0%	23	60.2%	36	21.5%	34	91%	19	30.2%	34
Wisconsin	1.5%	5	60.7%	37	14.5%	14	93%	8	27.7%	20
Wyoming	2.6%	18	67.3%	40	15.1%	15	89%	31	27.0%	17

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Support for Family Caregivers: Dimension and Indicator Ranking



Source: State Long-Term Services and Supports Scorecard, 2011.

Support for Family Caregivers: Indicator Performance and Ranking

	Percent of Caregivers Usually or Always Getting Needed Support		Legal and System Supports for Caregivers (Composite Indicator, Scale 0–12)		Number of Health Maintenance Tasks Able to be Delegated to LTSS Workers	
	2009	Rank	2010	Rank	2011	Rank
United States	**76.6%**					
Alabama	72.5%	49	1.04	49	4	29
Alaska	76.3%	40	3.00	28	8	21
Arizona	81.6%	4	3.60	18	*	*
Arkansas	78.4%	23	1.30	48	15	6
California	74.7%	46	5.50	5	2	32
Colorado	79.7%	13	3.50	21	16	1
Connecticut	79.6%	14	3.37	24	1	36
Delaware	78.3%	25	3.04	27	3	30
District of Columbia	77.1%	36	6.33	2	8	21
Florida	77.2%	34	4.10	13	0	41
Georgia	73.9%	47	5.10	7	*	*
Hawaii	77.3%	32	5.43	6	14	8
Idaho	81.4%	6	2.40	36	13	13
Illinois	75.1%	43	5.60	4	2	32
Indiana	76.0%	41	3.50	21	*	*
Iowa	81.6%	4	3.00	28	16	1
Kansas	81.1%	7	2.20	38	6	26
Kentucky	78.5%	22	2.95	31	6	26
Louisiana	75.1%	43	3.00	28	11	16
Maine	79.5%	16	3.96	14	9	20
Maryland	76.7%	38	2.00	39	14	8
Massachusetts	77.7%	31	3.17	26	2	32
Michigan	77.3%	32	4.60	12	0	41
Minnesota	81.7%	3	3.70	17	13	13
Mississippi	71.0%	51	5.10	7	3	30
Missouri	78.2%	26	3.60	18	16	1
Montana	78.8%	19	1.90	43	0	41
Nebraska	78.7%	20	2.30	37	16	1
Nevada	80.7%	10	3.20	25	15	6
New Hampshire	78.2%	26	2.60	34	8	21
New Jersey	75.6%	42	4.79	11	7	24
New Mexico	78.4%	23	2.00	39	*	*
New York	71.2%	50	1.60	44	11	16
North Carolina	77.8%	29	2.80	32	6	26
North Dakota	80.9%	9	1.50	47	13	13
Ohio	79.6%	14	2.00	39	7	24
Oklahoma	74.9%	45	2.00	39	0	41
Oregon	84.0%	1	6.43	1	16	1
Pennsylvania	77.1%	36	2.50	35	*	*
Rhode Island	78.6%	21	3.52	20	0	41
South Carolina	76.6%	39	3.71	16	1	36
South Dakota	80.5%	11	2.80	32	11	16
Tennessee	77.2%	34	5.10	7	1	36
Texas	73.2%	48	3.80	15	14	8
Utah	82.3%	2	1.00	50	1	36
Vermont	77.8%	29	3.38	23	1	36
Virginia	81.1%	7	1.60	44	2	32
Washington	79.2%	18	5.63	3	14	8
West Virginia	78.0%	28	0.50	51	0	41
Wisconsin	79.5%	16	1.59	46	14	8
Wyoming	80.3%	12	4.80	10	10	19

* Indicates data not available for this state.
Data: See Appendix B2 for a full description of each indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Legal and System Supports for Family Caregivers: Composite Indicator Rank and Component Scores

State	Exceeding Federal Minimum FMLA	Having Mandatory Paid Family and Sick Leave	Protecting Caregivers from Employment Discrimination	Spousal Impoverishment Provisions for Medicaid HCBS	Having a Caregiver Assessment	Overall Score	Rank
Alabama	0	0	0	1.04	0	1.04	49
Alaska	0	0	0	3.00	*	3.00	28
Arizona	0	0	0	1.50	2.10	3.60	18
Arkansas	0	0	0	1.00	0.30	1.30	48
California	0	2.50	0	3.00	0	5.50	5
Colorado	0	0	0.50	3.00	0	3.50	21
Connecticut	0.67	0	0	1.50	1.20	3.37	24
Delaware	0	0	0	1.54	1.50	3.04	27
District of Columbia	2.33	1.00	1.00	2.00	*	6.33	2
Florida	0	0	0	2.00	2.10	4.10	13
Georgia	0	0	0	3.00	2.10	5.10	7
Hawaii	0.33	0	0	3.00	2.10	5.43	6
Idaho	0	0	0	1.50	0.90	2.40	36
Illinois	0	0	0.50	3.00	2.10	5.60	4
Indiana	0	0	0	2.00	1.50	3.50	21
Iowa	0	0	0	3.00	0	3.00	28
Kansas	0	0	0	1.00	1.20	2.20	38
Kentucky	0.25	0	0	1.50	1.20	2.95	31
Louisiana	0	0	0	3.00	0	3.00	28
Maine	1.06	0	0	2.00	0.90	3.96	14
Maryland	0	0	0.50	1.50	0	2.00	39
Massachusetts	0.27	0	0	2.00	0.90	3.17	26
Michigan	0	0	0.50	2.00	2.10	4.60	12
Minnesota	0	0	0	1.60	2.10	3.70	17
Mississippi	0	0	0	3.00	2.10	5.10	7
Missouri	0	0	0	1.50	2.10	3.60	18
Montana	0	0	0	1.00	0.90	1.90	43
Nebraska	0	0	0	2.00	0.30	2.30	37
Nevada	0	0	0	2.00	1.20	3.20	25
New Hampshire	0	0	0	0.50	2.10	2.60	34
New Jersey	0.75	2.00	0	2.04	0	4.79	11
New Mexico	0	0	0	2.00	0	2.00	39
New York	0	0	0	1.60	*	1.60	44
North Carolina	0	0	0	1.00	1.80	2.80	32
North Dakota	0	0	0	1.50	*	1.50	47
Ohio	0	0	0	2.00	0	2.00	39
Oklahoma	0	0	0	2.00	0	2.00	39
Oregon	2.13	0	0.50	2.00	1.80	6.43	1
Pennsylvania	0	0	0	1.00	1.50	2.50	35
Rhode Island	0.52	0	0	3.00	0	3.52	20
South Carolina	0	0	0	2.51	1.20	3.71	16
South Dakota	0	0	0	1.00	1.80	2.80	32
Tennessee	0	0	0	3.00	2.10	5.10	7
Texas	0	0	0	2.00	1.80	3.80	15
Utah	0	0	0	1.00	0	1.00	50
Vermont	1.38	0	0	2.00	0	3.38	23
Virginia	0	0	0	1.00	0.60	1.60	44
Washington	1.73	0	0	1.80	2.10	5.63	3
West Virginia	0	0	0	0.50	0	0.50	51
Wisconsin	0.09	0	0	1.50	0	1.59	46
Wyoming	0	0	0	3.00	1.80	4.80	10

* AK, DC, NY, and ND did not respond to the AARP state survey and therefore data were not available for this element.
Note: FMLA = Family and Medical Leave Act.
Data: See Appendix B2 for a full description of this indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Exhibit A14

Health Maintenance Tasks Able to be Delegated to LTSS Workers

	Administer Oral Medications	Administer Medication on an as Needed Basis	Administer Medication via Pre-Filled Insulin or Insulin Pen	Draw Up Insulin for Dosage Measurement	Administer Intramuscular Injection Mediations	Administer Glucometer Test	Administer Medication through Tubes	Insert Suppository
Alabama						Y		
Alaska	Y	Y				Y	Y	Y
Arizona	*	*	*	*	*	*	*	*
Arkansas	Y	Y	Y	Y		Y	Y	Y
California						Y		
Colorado	Y	Y	Y	Y	Y	Y	Y	Y
Connecticut								
Delaware						Y		
District of Columbia	Y	Y	Y					Y
Florida								
Georgia	*	*	*	*	*	*	*	*
Hawaii	Y	Y	Y			Y	Y	Y
Idaho	Y	Y				Y	Y	Y
Illinois						Y		
Indiana	*	*	*	*	*	*	*	*
Iowa	Y	Y	Y	Y	Y	Y	Y	Y
Kansas						Y		Y
Kentucky	Y					Y		Y
Louisiana	Y					Y	Y	
Maine	Y		Y			Y		Y
Maryland	Y	Y	Y	Y		Y	Y	Y
Massachusetts						Y		
Michigan								
Minnesota	Y	Y				Y	Y	Y
Mississippi						Y		
Missouri	Y	Y	Y	Y	Y	Y	Y	Y
Montana								
Nebraska	Y	Y	Y	Y	Y	Y	Y	Y
Nevada	Y	Y	Y	Y	Y	Y	Y	Y
New Hampshire						Y	Y	Y
New Jersey								
New Mexico	*	*	*	*	*	*	*	*
New York	Y	Y	Y	Y	Y	Y	Y	
North Carolina						Y		
North Dakota	Y	Y	Y	Y	Y	Y	Y	Y
Ohio						Y		Y
Oklahoma								
Oregon	Y	Y	Y	Y	Y	Y	Y	Y
Pennsylvania	*	*	*	*	*	*	*	*
Rhode Island								
South Carolina								
South Dakota	Y	Y				Y		Y
Tennessee								
Texas	Y	Y	Y	Y		Y	Y	Y
Utah								
Vermont						Y		
Virginia						Y		
Washington	Y	Y	Y	Y		Y	Y	Y
West Virginia								
Wisconsin	Y	Y	Y			Y	Y	Y
Wyoming	Y	Y				Y	Y	Y

*Indicates data not available for this state.
Note: A blank space indicates that the state does not permit delegation of this health maintenance task to LTSS workers.
Data: See Appendix B2 for a full description of this indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

Exhibit A14 (continued)

Health Maintenance Tasks Able to be Delegated to LTSS Workers

	Administer Eye/Ear Drops	Gastrostomy Tube Feeding	Administer Enema	Perform Intermittent Catheterization	Perform Ostomy Care Including Skin Care and Changing Appliance	Perform Nebulizer Treatment	Administer Oxygen Therapy	Perform Ventilator Respiratory Care	Total Number of Tasks Able to be Delegated	Rank
Alabama					Y	Y	Y		4	29
Alaska	Y	Y			Y				8	21
Arizona	*	*	*	*	*	*	*	*	*	*
Arkansas	Y	Y	Y	Y	Y	Y	Y	Y	15	6
California			Y						2	32
Colorado	Y	Y	Y	Y	Y	Y	Y	Y	16	1
Connecticut					Y				1	36
Delaware				Y	Y				3	30
District of Columbia	Y		Y		Y	Y			8	21
Florida									0	41
Georgia	*	*	*	*	*	*	*	*	*	*
Hawaii	Y	Y	Y	Y	Y	Y	Y	Y	14	8
Idaho	Y	Y	Y	Y	Y	Y	Y	Y	13	13
Illinois					Y				2	32
Indiana	*	*	*	*	*	*	*	*	*	*
Iowa	Y	Y	Y	Y	Y	Y	Y	Y	16	1
Kansas	Y		Y	Y			Y		6	26
Kentucky	Y			Y	Y				6	26
Louisiana	Y	Y	Y	Y	Y	Y	Y	Y	11	16
Maine	Y	Y	Y	Y	Y				9	20
Maryland	Y	Y	Y	Y	Y	Y	Y		14	8
Massachusetts					Y				2	32
Michigan									0	41
Minnesota	Y	Y	Y	Y	Y	Y	Y	Y	13	13
Mississippi			Y	Y					3	30
Missouri	Y	Y	Y	Y	Y	Y	Y	Y	16	1
Montana									0	41
Nebraska	Y	Y	Y	Y	Y	Y	Y	Y	16	1
Nevada	Y	Y	Y	Y	Y	Y	Y		15	6
New Hampshire		Y	Y	Y	Y		Y		8	21
New Jersey		Y	Y	Y	Y	Y	Y	Y	7	24
New Mexico	*	*	*	*	*	*	*	*	*	*
New York		Y	Y		Y		Y		11	16
North Carolina		Y	Y	Y	Y		Y		6	26
North Dakota	Y	Y	Y	Y	Y				13	13
Ohio	Y	Y	Y	Y	Y				7	24
Oklahoma									0	41
Oregon	Y	Y	Y	Y	Y	Y	Y	Y	16	1
Pennsylvania	*	*	*	*	*	*	*	*	*	*
Rhode Island									0	41
South Carolina			Y						1	36
South Dakota	Y	Y	Y	Y	Y	Y	Y		11	16
Tennessee			Y						1	36
Texas	Y	Y	Y	Y	Y	Y	Y		14	8
Utah					Y				1	36
Vermont									1	36
Virginia					Y				2	32
Washington	Y		Y	Y	Y	Y	Y	Y	14	8
West Virginia									0	41
Wisconsin	Y	Y	Y	Y	Y	Y	Y	Y	14	8
Wyoming	Y	Y	Y		Y		Y		10	19

*Indicates data not available for this state.
Note: A blank space indicates that the state does not permit delegation of this health maintenance task to LTSS workers.
Data: See Appendix B2 for a full description of this indicator.
Source: State Long-Term Services and Supports Scorecard, 2011.

State Demographics: Age of Population (2009)

State	All Ages	Percent <Age 18	Percent Age 18–64	Percent Age 65+
United States	**307,006,550**	**24.3%**	**62.8%**	**12.9%**
Alabama	4,708,708	24.0%	62.2%	13.8%
Alaska	698,473	26.3%	66.2%	7.6%
Arizona	6,595,778	26.3%	60.6%	13.1%
Arkansas	2,889,450	24.6%	61.1%	14.3%
California	36,961,664	25.5%	63.2%	11.2%
Colorado	5,024,748	24.4%	64.9%	10.6%
Connecticut	3,518,288	23.0%	63.2%	13.9%
Delaware	885,122	23.4%	62.3%	14.3%
District of Columbia	599,657	19.0%	69.3%	11.7%
Florida	18,537,969	21.9%	60.9%	17.2%
Georgia	9,829,211	26.3%	63.4%	10.3%
Hawaii	1,295,178	22.4%	63.1%	14.5%
Idaho	1,545,801	27.1%	60.8%	12.1%
Illinois	12,910,409	24.6%	63.0%	12.4%
Indiana	6,423,113	24.7%	62.4%	12.9%
Iowa	3,007,856	23.7%	61.5%	14.8%
Kansas	2,818,747	25.0%	62.0%	13.0%
Kentucky	4,314,113	23.5%	63.3%	13.2%
Louisiana	4,492,076	25.0%	62.7%	12.3%
Maine	1,318,301	20.6%	63.8%	15.6%
Maryland	5,699,478	23.7%	64.1%	12.2%
Massachusetts	6,593,587	21.7%	64.7%	13.6%
Michigan	9,969,727	23.6%	63.0%	13.4%
Minnesota	5,266,214	23.9%	63.3%	12.7%
Mississippi	2,951,996	26.0%	61.2%	12.8%
Missouri	5,987,580	23.9%	62.4%	13.7%
Montana	974,989	22.5%	62.9%	14.6%
Nebraska	1,796,619	25.1%	61.5%	13.4%
Nevada	2,643,085	25.8%	62.6%	11.6%
New Hampshire	1,324,575	21.8%	64.6%	13.5%
New Jersey	8,707,739	23.5%	63.0%	13.5%
New Mexico	2,009,671	25.4%	61.6%	13.0%
New York	19,541,453	22.6%	64.0%	13.4%
North Carolina	9,380,884	24.3%	63.0%	12.7%
North Dakota	646,844	22.3%	63.1%	14.7%
Ohio	11,542,645	23.5%	62.6%	13.9%
Oklahoma	3,687,050	24.9%	61.6%	13.5%
Oregon	3,825,657	22.8%	63.7%	13.5%
Pennsylvania	12,604,767	22.0%	62.5%	15.4%
Rhode Island	1,053,209	21.5%	64.2%	14.3%
South Carolina	4,561,242	23.7%	62.6%	13.7%
South Dakota	812,383	24.6%	60.9%	14.5%
Tennessee	6,296,254	23.7%	62.9%	13.4%
Texas	24,782,302	27.8%	61.9%	10.2%
Utah	2,784,572	31.2%	59.8%	9.0%
Vermont	621,760	20.3%	65.2%	14.5%
Virginia	7,882,590	23.4%	64.4%	12.2%
Washington	6,664,195	23.6%	64.3%	12.1%
West Virginia	1,819,777	21.2%	63.0%	15.8%
Wisconsin	5,654,774	23.2%	63.4%	13.5%
Wyoming	544,270	24.3%	63.5%	12.3%

Data: U.S. Census Bureau 2009 Population Estimates.
Source: State Long-Term Services and Supports Scorecard, 2011.

State Demographics: Median Household Income and Poverty (2009)

	Median Household Income		Percent Below Poverty Level			Percent At/Below 250% of Poverty Level		
	All Ages	Householder Age 65+	All Ages	Age 18+	Age 65+	All Ages	Age 18+	Age 65+
United States	**$50,221**	**$33,712**	**14.3%**	**12.5%**	**9.5%**	**41.5%**	**38.3%**	**42.1%**
Alabama	$40,489	$29,107	17.5%	15.2%	11.3%	48.0%	44.9%	49.2%
Alaska	$66,953	$47,296	9.0%	7.7%	3.2%	30.2%	26.3%	28.9%
Arizona	$48,745	$36,855	16.5%	14.1%	8.4%	45.7%	41.4%	39.0%
Arkansas	$37,823	$27,422	18.8%	16.0%	12.0%	51.6%	47.8%	52.1%
California	$58,931	$39,891	14.2%	12.2%	8.7%	42.2%	38.5%	38.7%
Colorado	$55,430	$37,284	12.9%	11.4%	8.6%	36.6%	33.8%	37.1%
Connecticut	$67,034	$39,582	9.4%	8.6%	6.4%	28.2%	26.4%	32.8%
Delaware	$56,860	$38,240	10.8%	9.1%	6.5%	37.0%	33.6%	35.8%
District of Columbia	$59,290	$42,495	18.4%	15.7%	14.6%	40.1%	35.6%	39.8%
Florida	$44,736	$34,214	14.9%	13.1%	10.2%	45.6%	42.6%	43.1%
Georgia	$47,590	$31,107	16.5%	14.4%	11.9%	45.2%	41.7%	44.7%
Hawaii	$64,098	$50,784	10.4%	9.4%	7.3%	32.1%	29.5%	30.4%
Idaho	$44,926	$32,084	14.3%	12.8%	8.3%	49.5%	45.5%	44.9%
Illinois	$53,966	$34,261	13.3%	11.5%	8.7%	38.6%	35.4%	40.3%
Indiana	$45,424	$31,505	14.4%	12.5%	7.9%	42.9%	39.5%	43.7%
Iowa	$48,044	$31,863	11.8%	10.6%	7.3%	38.1%	35.7%	43.5%
Kansas	$47,817	$32,368	13.4%	11.9%	7.8%	41.3%	38.0%	42.6%
Kentucky	$40,072	$27,078	18.6%	16.4%	12.7%	48.6%	45.3%	50.6%
Louisiana	$42,492	$28,485	17.3%	14.9%	12.4%	46.2%	43.2%	48.3%
Maine	$45,734	$29,518	12.3%	11.1%	8.8%	42.4%	39.9%	47.8%
Maryland	$69,272	$44,486	9.1%	8.3%	7.9%	28.6%	26.4%	31.2%
Massachusetts	$64,081	$34,764	10.3%	9.5%	8.8%	29.6%	28.3%	39.2%
Michigan	$45,255	$32,668	16.2%	14.2%	8.5%	43.5%	40.5%	42.4%
Minnesota	$55,616	$34,000	11.0%	10.0%	8.6%	33.8%	31.8%	40.7%
Mississippi	$36,646	$24,999	21.9%	18.7%	15.0%	54.3%	50.5%	55.9%
Missouri	$45,229	$31,586	14.6%	12.6%	8.6%	43.2%	40.0%	44.1%
Montana	$42,322	$30,964	15.1%	13.2%	8.7%	46.8%	43.4%	44.0%
Nebraska	$47,357	$32,248	12.3%	11.4%	7.8%	39.6%	37.0%	41.2%
Nevada	$53,341	$37,015	12.4%	10.5%	7.5%	42.1%	38.1%	39.8%
New Hampshire	$60,567	$36,548	8.5%	7.9%	6.7%	29.5%	28.0%	37.1%
New Jersey	$68,342	$39,553	9.4%	8.1%	7.9%	29.0%	26.9%	34.2%
New Mexico	$43,028	$32,831	18.0%	15.4%	12.2%	49.7%	45.4%	44.9%
New York	$54,659	$33,882	14.2%	12.4%	11.3%	38.3%	35.5%	42.1%
North Carolina	$43,674	$31,064	16.3%	14.2%	10.0%	45.8%	42.7%	45.3%
North Dakota	$47,827	$29,853	11.7%	11.3%	11.5%	36.1%	35.0%	44.9%
Ohio	$45,395	$31,380	15.2%	13.2%	8.4%	42.7%	39.4%	43.5%
Oklahoma	$41,664	$31,028	16.2%	14.2%	9.5%	48.1%	44.2%	45.9%
Oregon	$48,457	$33,865	14.3%	12.8%	8.4%	43.1%	40.1%	41.9%
Pennsylvania	$49,520	$30,937	12.5%	11.1%	8.8%	38.2%	35.5%	44.9%
Rhode Island	$54,119	$32,520	11.5%	9.9%	9.1%	35.3%	32.5%	41.8%
South Carolina	$42,442	$32,150	17.1%	14.7%	11.2%	47.6%	44.0%	45.3%
South Dakota	$45,043	$30,138	14.2%	12.8%	10.6%	43.6%	40.5%	46.0%
Tennessee	$41,725	$29,495	17.1%	15.0%	11.1%	47.4%	44.3%	48.2%
Texas	$48,259	$33,613	17.2%	14.3%	11.8%	47.1%	42.9%	44.3%
Utah	$55,117	$39,569	11.5%	11.2%	7.4%	42.4%	38.6%	37.0%
Vermont	$51,618	$33,076	11.4%	10.9%	7.8%	36.7%	34.5%	44.1%
Virginia	$59,330	$38,920	10.5%	9.5%	8.2%	33.1%	30.8%	35.6%
Washington	$56,548	$39,249	12.3%	11.1%	7.7%	36.6%	33.9%	35.5%
West Virginia	$37,435	$25,984	17.7%	16.1%	10.3%	49.6%	47.6%	57.0%
Wisconsin	$49,993	$32,172	12.4%	11.1%	7.7%	37.9%	35.2%	42.5%
Wyoming	$52,664	$34,343	9.8%	9.0%	6.4%	36.0%	32.7%	36.6%

Data: 2009 American Community Survey, AARP Public Policy Institute analysis of 2009 ACS Public Use Microdata Sample.
Source: State Long-Term Services and Supports Scorecard, 2011.

State Demographics: Disability (2009)

	Proportion of People Age 18–64 with ADL Disability	Proportion of People Age 65+ with ADL Disability	Proportion of People Age 18–64 with Any Disability	Proportion of People Age 65+ with Any Disability
United States	**1.8%**	**8.8%**	**10.1%**	**37.4%**
Alabama	2.7%	11.2%	14.8%	44.3%
Alaska	1.7%	10.0%	11.0%	45.4%
Arizona	1.9%	7.8%	9.7%	36.6%
Arkansas	2.8%	10.3%	16.1%	44.6%
California	1.5%	10.5%	8.1%	37.6%
Colorado	1.3%	7.0%	8.1%	34.8%
Connecticut	1.3%	7.1%	8.4%	31.8%
Delaware	1.6%	6.8%	10.9%	36.1%
District of Columbia	1.7%	8.7%	10.2%	36.5%
Florida	1.8%	8.0%	9.7%	35.5%
Georgia	1.7%	9.8%	10.3%	39.6%
Hawaii	1.2%	8.1%	7.7%	36.1%
Idaho	1.7%	6.9%	10.8%	38.1%
Illinois	1.5%	7.9%	7.9%	35.7%
Indiana	1.7%	7.5%	10.8%	38.1%
Iowa	1.3%	6.3%	9.1%	33.6%
Kansas	1.7%	7.9%	10.4%	38.0%
Kentucky	2.5%	9.7%	15.6%	43.8%
Louisiana	2.2%	12.0%	12.8%	43.2%
Maine	2.0%	8.1%	13.9%	39.4%
Maryland	1.3%	7.5%	8.2%	33.1%
Massachusetts	1.5%	7.2%	8.9%	34.0%
Michigan	2.3%	8.3%	11.8%	36.9%
Minnesota	1.4%	6.0%	8.1%	31.9%
Mississippi	2.6%	12.2%	14.5%	46.2%
Missouri	2.3%	8.7%	12.4%	39.3%
Montana	1.6%	6.4%	11.2%	38.1%
Nebraska	1.3%	6.3%	8.8%	34.9%
Nevada	1.6%	7.8%	8.6%	33.7%
New Hampshire	1.4%	6.8%	8.9%	36.8%
New Jersey	1.4%	8.4%	7.7%	33.7%
New Mexico	2.1%	9.5%	12.0%	42.3%
New York	1.6%	9.3%	8.8%	35.1%
North Carolina	2.0%	9.2%	11.3%	39.0%
North Dakota	1.2%	5.9%	9.0%	36.1%
Ohio	2.1%	8.1%	11.7%	36.9%
Oklahoma	2.5%	9.1%	14.6%	42.4%
Oregon	1.9%	8.7%	10.8%	37.9%
Pennsylvania	1.7%	7.6%	10.7%	35.8%
Rhode Island	1.6%	6.5%	10.2%	33.7%
South Carolina	2.2%	10.0%	11.9%	40.0%
South Dakota	1.3%	5.4%	9.1%	34.9%
Tennessee	2.3%	10.5%	13.5%	42.1%
Texas	1.9%	10.9%	9.9%	41.6%
Utah	1.2%	7.3%	8.0%	35.5%
Vermont	1.7%	8.5%	11.5%	35.6%
Virginia	1.6%	7.9%	9.0%	35.5%
Washington	1.8%	8.6%	10.4%	38.0%
West Virginia	3.0%	10.2%	17.2%	45.3%
Wisconsin	1.5%	6.7%	8.8%	32.8%
Wyoming	1.3%	6.4%	11.0%	39.8%

Data: 2009 American Community Survey.
Source: State Long-Term Services and Supports Scorecard, 2011.

Appendix B.1 *Scorecard* Advisory Process

During the initial phase of the *Scorecard* project, AARP formed two advisory bodies: a National Advisory Panel (NAP) and a Technical Advisory Panel (TAP). Members of the NAP were as follows:

- Lisa Alecxih of The Lewin Group
- Brian Burwell of Thomson Reuters
- Penny Feldman of the Visiting Nurse Service of New York
- Lynn Friss Feinberg, formerly of the National Partnership for Women and Families
- Melissa Hulbert of the Centers for Medicare & Medicaid Services
- Rosalie Kane of the University of Minnesota
- Ruth Katz of the U.S. Department of Health and Human Services
- James Knickman of the New York State Health Foundation
- Joseph Lugo of the Administration on Aging
- William Scanlon of National Health Policy Forum

The purpose of the NAP was to provide expert guidance to the *Scorecard* team from a broad range of knowledgeable stakeholders. Its first tasks were to develop a working definition of long-term services and supports (LTSS) and a vision of what would constitute a high-performing LTSS system. For this purpose, we contracted with Harriet Komisar, then of the Hilltop Institute, to review the literature and develop two discussion papers to guide the deliberations among the AARP project team, the funders, and the members of the NAP. At the first NAP meeting, the consensus definition of LTSS that is used in this report was developed. The second NAP meeting established the vision of a high-performing system, comprised of the five characteristics articulated in the report. Throughout the project, the *Scorecard* team consulted with NAP members individually, in small groups, and as a whole at critical decision points.

Advice from the NAP was augmented by individual interviews and group discussion with additional stakeholders, to ensure representation of diverse views and areas of expertise. These individuals are acknowledged at the beginning of the report.

The Technical Advisory Panel (TAP) was formed to provide advice specifically on the data that would comprise the *Scorecard*. Members of the TAP were selected for either their overall expertise in LTSS data or for their particular background in specific aspects of LTSS data. To facilitate cross-communication in the advisory process, two individuals (Lisa Alecxih and Brian Burwell) served on both the NAP and TAP. Members of the TAP were as follows:

- Lisa Alecxih of The Lewin Group
- Robert Applebaum of Miami University of Ohio
- Brian Burwell of Thomson Reuters
- Charlene Harrington of the University of California San Francisco
- Lauren Harris-Kojetin of the National Center for Health Statistics
- Carol Irvin of Mathematica Policy Research, Inc.
- Kathy Leitch, formerly of the Washington State Aging and Disability Services Administration
- Chuck Milligan, formerly of the Hilltop Institute

- Terry Moore of Abt Associates
- Vince Mor of Brown University
- D. E. B. Potter of the Agency for Healthcare Research and Quality

The initial TAP meeting was convened to explore which data were considered most important and which data would be most feasible to obtain. After a comprehensive list of possible data indicators was developed, participants were polled to establish an initial target list of indicators for inclusion in the *Scorecard*. In consultation with the TAP, the *Scorecard* team determined that the data selected must be clear, unambiguous, important, meaningful, and available at the state level. Throughout the project, members of the TAP were consulted individually, in small groups, and as a whole to assist in the final selection of the 25 indicators that comprise the *Scorecard*. The TAP was consulted not only in the selection of indicators, but in determining which indicators would meaningfully comprise each dimension.

Finally, NAP and TAP members reviewed and commented on the *Scorecard* report and its findings. While the NAP and TAP provided guidance throughout the process, the responsibility for final decisions rested with the *Scorecard* team at AARP in consultation with our funders. Any errors or omissions are the responsibility of the authors.

Appendix B.2. State LTSS Scorecard Indicator Descriptions and Data Sources

Complete references for data sources are provided in Appendix B.3

Indicator	Description
1	**Median annual nursing home private pay cost as a percentage of median household income ages 65+:** The ratio of the median daily private room rate (multiplied by 365 days) divided by the median household income for households headed by someone age 65+. Cost data are from the 2010 Genworth Cost of Care Survey (Genworth, 2010), and income data from AARP Public Policy Institute analysis of the 2009 American Community Survey Public Use Microdata Sample (U.S. Census Bureau, ACS PUMS 2009). The ratio of the median nursing home cost to median income was calculated at the "region" level (436 markets defined by Genworth that cover the entire United States) and then averaged across all regions in a state, weighted by the proportion of the state population in each region.
2	**Median annual home care private pay cost as a percentage of median household income ages 65+:** The ratio of the median annual private pay cost of licensed home health aide services (based on 30 hours of care per week, multiplied by 52 weeks) divided by the median household income for households headed by someone age 65+. Cost data are from the 2010 Genworth Cost of Care Survey (Genworth, 2010), and income data from AARP Public Policy Institute analysis of the 2009 American Community Survey Public Use Microdata Sample (U.S. Census Bureau, ACS PUMS 2009). The ratio of the median nursing home cost to median income was calculated at the "region" level (436 markets defined by Genworth that cover the entire United States) and then averaged across all regions in a state, weighted by the proportion of the state population in each region.
3	**Private long-term care insurance policies in effect per 1,000 persons age 40+:** Number of individual and group private long-term care insurance policies in force (for persons of all ages) per 1,000 population age 40 or older in the state. Data obtained from LIMRA Individual and Group In-Force Lives, Long-Term Care Insurance Policies in Effect report (LIMRA, 2009) and U.S. Census Bureau population estimates (U.S. Census Bureau, 2009). This is not exactly the proportion of persons age 40+ with private LTCI since data on the age of policy-holders at the state level are not available. 75% of group policy-holders and 94% of individual policy-holders are age 40 or older.
4	**Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance:** Percent of adults age 21 or older with a self-care difficultly (difficulty dressing or bathing; a reasonable approximation to ADL disability) at or below 250% of the poverty threshold who have health insurance through Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability. 250% of poverty was chosen in order to fully capture the effect of state policies extending Medicaid eligibility for LTSS up to 300% of SSI. AARP Public Policy Institute analysis of 2009 American Community Survey Public Use Microdata Sample (U.S. Census Bureau, ACS PUMS 2009).
5	**Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community:** The number of participant-months (divided by 12) of Medicaid LTSS for adults age 65+ or age 21+ with a physical disability divided per 100 persons age 21+ with a self-care difficultly at or below 250% of the poverty threshold, or of any age living in a nursing home. 250% of poverty was chosen in order to fully capture the effect of state policies extending Medicaid eligibility for LTSS up to 300% of SSI. LTSS participant years from Mathematica Policy Research analysis of 2006 and 2007 Medicaid Analytic Extract (CMS, MAX 2006, 2007). Participants must have met the following criteria: they were either 65 or older by December 31, 2007, or were 21–64 by December 31, 2007, and (1) had an eligibility code of "disabled/blind," (2) did not use ICF-MR or psychiatric facility services, and (3) were not enrolled in a 1915(c) waiver for people with MR/DD or mental illness. Beneficiaries were determined to be users of institutional services during a month if they had a claim in the 2007 MAX LT file indicating a nursing home stay; they were determined to be users of HCBS if their records in the 2007 PS or OT files indicated they were enrolled in a 1915(c) waiver or used waiver services or had claims that indicated the use of state plan personal care services, residential care, adult day care, in-home private duty nursing, or at least four consecutive months of home health care. In order to assess whether home health care services provided during January, February, and March 2007 were part of a block of four consecutive months of service, home health use in October, November, and December 2006 was also analyzed. Denominator population from AARP Public Policy Institute analysis of 2007 American Community Survey Public Use Microdata Sample (U.S. Census Bureau, ACS PUMS 2007) for community residents and analysis of CMS Online Survey and Certification Reporting by C. Harrington and H. Carrillo, reported in AARP Public Policy Institute, Across the States 2009 (CMS, OSCAR 2006, 2007) for nursing home residents.

Appendix B.2. State LTSS Scorecard Indicator Descriptions and Data Sources (continued)

Complete references for data sources are provided in Appendix B.3

Indicator	Description
6	**ADRC/Single Entry Point functionality (composite indicator, scale 0–12):** This indicator is constructed from two sources of data: (1) data reported to The Lewin Group for the Aging and Disability Resource Centers (ADRCs) and (2) data collected by the AARP survey on single entry point/no wrong door (SEP) systems in each state. The constructed indicator scores states on a continuous scale from 0 (absent or nonfunctional) to 1 (fully functional) on 12 functions typically provided by ADRCs and other SEPs. The 12 functions are— 1. Serving all age and disability populations and private paying population and partnerships 2. Continuous quality improvement 3. Formal marketing and outreach 4. Systematic information and referral/assistance 5. Options counseling and assistance 6. Coordination of eligibility processes and tracking eligibility status 7. Intake and screening 8. Nursing facility pre-admission screening 9. Financial eligibility determination 10. Level of care/functional eligibility determination 11. Service planning and delivery 12. Institutional transitions and acute-care/hospital transition services A composite score for each of the 12 functions was derived by assigning a point value to each of 26 elements of the Criteria for Fully Functional ADRCs established by The Lewin Group and to 16 questions from the *State LTSS Scorecard Survey* on functions performed by other SEP systems. States were given full credit, half credit, or no credit for each Fully Functional Criterion in which they were assessed as "fully meets," "partially meets," or "area for improvement." States were given full or no credit for their SEP survey responses depending upon whether or not the state reported performing a function. State scores for each function were summed across all elements and then divided by the maximum possible score. Approximately two-thirds of the total composite score is based on ADRC functionality, and one third is based on SEP functionality, if not part of ADRC functionality. This indicator ranks the states on the number and type of functions that ADRCs and SEPs perform. It does not evaluate how well these functions are performed, whether they are carried out consistently, or whether the ADRCs and other SEP systems are available statewide. Data sources include the *State LTSS Scorecard Survey* (AARP PPI, Scorecard 2010) and The Lewin Group assessment of ADRC grantees' progress toward reaching Fully Functional Status (The Lewin Group, 2011a). AARP conducted a state survey to collect information about states' single entry point systems and various functions that facilitate consumer choice. Forty-seven states responded to the survey. The survey collected data on whether the state performed specified functions, but did not evaluate how well or how thoroughly these functions are carried out.
6 continued	ADRCs are funded through federal grants to states and thus are subject to federal reporting requirements. The Lewin Group is the contractor charged with collecting these data. As part of this process, The Lewin Group reviews all reports, documentation, and supporting materials and conducts telephone interviews with each grantee. As an additional source of data, the Streamlining Access survey (The Lewin Group, 2011b) was the source of information about nursing facility pre-admission screening for states that did not complete the SEP Survey.
7	**Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities:** Proportion of Medicaid LTSS and home health spending for older people and adults with physical disabilities (defined as nursing homes, personal care, aged/disabled waivers, home health, and other programs used primarily by older people and adults with physical disabilities) going to HCBS, including Medicaid and state-funded services. Because of data limitations, 2008 data were used for Hawaii, New Mexico, and Rhode Island, and 2007 data were used for Arizona. Medicaid fee-for-service spending from *Medicaid Long-Term Care Expenditures FY 2009* (Thomson Reuters, 2010). Medicaid managed care spending from *Medicaid Managed Long-Term Services and Supports Expenditures* (Thomson Reuters, 2011); where "waiver-equivalent" spending was small, it was allocated 50/50 between aged/disabled and MR/DD populations; for Wisconsin, the aged/disabled amount was calculated from the Department of Health Services annual reports. State-funded LTSS from AARP Public Policy Institute, Weathering the Storm (AARP PPI, 2011). Arizona data from AARP Public Policy Institute, Across the States 2009 (AARP PPI, 2009).
8	**Percent of new Medicaid LTSS users first receiving services in the community:** Proportion of Medicaid LTSS beneficiaries in 2007 who did not receive any LTSS in 2006, who in the first calendar month of receiving LTSS received HCBS only and not institutional services. Participants must have met the following criteria: they were either 65 or older by December 31, 2007, or were 21–64 by December 31, 2007, and (1) had an eligibility code of "disabled/blind," (2) did not use ICF-MR or psychiatric facility services, and (3) were not enrolled in a 1915(c) waiver for people with MR/DD or mental illness. Beneficiaries were determined to be users of institutional services during a month if they had a claim in the 2007 MAX LT file indicating a nursing home stay; they were determined to be users of HCBS if their records in the 2007 PS or OT files indicated they were enrolled in a 1915(c) waiver, used waiver services, or had claims that indicated the use of state plan personal care services, residential care, adult day care, in-home private duty nursing, or at least four consecutive months of home health care. In order to assess whether home health care services provided during January, February, and March 2007 were part of a block of four consecutive months of service, home health use in October, November, and December 2006 was also analyzed. Mathematica Policy Research analysis of 2006 and 2007 Medicaid Analytic Extract (CMS, MAX 2006, 2007).

Appendix B.2. State LTSS Scorecard Indicator Descriptions and Data Sources (continued)

Complete references for data sources are provided in Appendix B.3

Indicator	Description
9	**Number of people consumer-directing services per 1,000 adults age 18+ with disabilities**: Reported as number receiving consumer-directed services per 1,000 people with disabilities. Note that not all people with disabilities have LTSS needs. Number of people receiving consumer-directed services from data reported in *Financial Management Services in Participant Direction Programs* (SCAN, 2011). Number of people with disabilities from 2009 *American Community Survey* (U.S. Census Bureau, ACS 2009).
10	**Tools and programs to facilitate consumer choice (composite indicator, scale 0–4):** States were scored from 0 (no use of tool or program) to 1 (full use of tool or program) in each of four categories: 1. Presumptive eligibility (scoring: 1 point) 2. Uniform assessment (scoring: proportion of Medicaid and state-funded programs that use a uniform assessment tool, with multiple HCBS waivers counting as two programs regardless of the number of waivers) 3. Money Follows the Person and other nursing facility transition programs (scoring: 1/3 point if a program exists, 1/3 point if statewide, 1/3 point if it pays for one-time costs to establish community residence) 4. Options counseling (scoring: whether offered to individuals using each of five types of payment source) AARP conducted a state survey to collect information about states' single entry point systems and various functions that facilitate consumer choice. Forty-seven states responded to the survey. The survey collected data on whether the state performed specified functions, but did not evaluate how well or how thoroughly these functions are carried out. Data from *State LTSS Scorecard Survey* (AARP PPI, Scorecard 2010).
11	**Home health and personal care aides per 1,000 people age 65+:** Number of personal, home care, and home health aide direct care workers per 1,000 population age 65 or older. Data from 2009 Occupational Employment Statistics (BLS, OES 2009) and U.S. Census Bureau 2009 population estimates (U.S. Census Bureau, 2009).
12	**Assisted living and residential care units per 1,000 people age 65+:** Number of assisted living and residential care units per population age 65 or older. Data from *State LTSS Scorecard Survey* (AARP PPI, Scorecard 2010) and U.S. Census Bureau 2009 population estimates (U.S. Census Bureau, 2009). Data are not available for Connecticut because the state licenses Assisted Living Service Agencies (ALSAs) rather than facilities and the number of units covered by ALSAs is not reported.

Indicator	Description
13	**Percentage of nursing home residents with low care needs:** Percentage of nursing home residents age 65 and older who met the criteria of having low care needs. Low care status is met if a resident does not require physical assistance in any of the four late-loss ADLs (bed mobility, transferring, using the toilet, and eating) and is not classified in either the "Special Rehab" or "Clinically Complex" Resource Utilization Group (RUG-III) groups. Low care status may apply to a resident who is also classified in either of the lowest two of the 44 RUG-III groups. Analysis of MDS as reported in LTCFocUS.org, by V. Mor at Brown University, under a grant funded by the National Institute on Aging Program Project grant (#P01-AG027296, Shaping Long Term Care in America). State-Level Care Data (CMS, MDS n.d.).
14	**Percent of adults age 18+ with disabilities in the community usually or always getting needed support:** Percent of adults limited in any way in any activities because of physical, mental, or emotional problems who usually or always received needed social and emotional support. Data from 2009 BRFSS (NCCDPHP, BRFSS 2009).
15	**Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life:** Percent of adults limited in any way in any activities because of physical, mental, or emotional problems who were satisfied or very satisfied with their life. Data from 2009 BRFSS (NCCDPHP, BRFSS 2009).
16	**Rate of employment for adults with ADL disability age 18–64 relative to rate of employment for adults without ADL disability age 18–64:** Relative rate of employment (full or part time) for people age 18–64 with a self-care difficulty (difficulty dressing or bathing; a reasonable approximation to ADL disability) compared to people age 18–64 without self-care difficulty. Employment rate is calculated as the percentage of all people who are employed, including those who are not in the labor force, as many people with disabilities are not in the labor force, even though they may have the skills and desire to work. Data from 2009 American Community Survey (U.S. Census Bureau, ACS 2009).
17	**Percent of high-risk nursing home residents with pressure sores:** Percent of long-stay nursing home residents impaired in bed mobility or transfer, comatose, or suffering malnutrition who have pressure sores (stage 1–4) on target assessment. Data from CMS, Nursing Home Minimum Data Set (CMS, MDS n.d.), reported in *National Healthcare Quality and Disparities Reports* (AHRQ, 2009).
18	**Percent of long-stay nursing home residents who were physically restrained:** Percent of long-stay nursing home residents who were physically restrained daily on target assessment. Data from CMS, Nursing Home Minimum Data Set (CMS, MDS n.d.), reported in *National Healthcare Quality and Disparities Reports* (AHRQ, 2009).

Appendix B.2. State LTSS Scorecard Indicator Descriptions and Data Sources (continued)

Complete references for data sources are provided in Appendix B.3.

Indicator	Description
19	**Nursing home staffing turnover: ratio of employee terminations to the average number of active employees:** The ratio of full- and part-time employee terminations that occurred during the year, regardless of cause, to the average number of active employees on the payroll during the same time period. Data from American Health Care Association, reported in *Report of Findings: 2008 Nursing Facility Staff Vacancy, Retention and Turnover Survey* (AHCA, 2010).
20	**Percent of long-stay nursing home residents with a hospital admission:** Percent of long-stay residents (residing in a nursing home relatively continuously for 100 days prior to the second quarter of the calendar year) who were ever hospitalized within six months of baseline assessment. Analysis of Medicare enrollment data and MEDPAR file by V. Mor at Brown University, under a grant funded by the National Institute on Aging Program Project grant (#P01-AG027296, Shaping Long Term Care in America) (CMS, MEDPAR 2008).
21	**Percent of home health episodes of care in which interventions to prevent pressure sores were included in the plan of care for at-risk patients:** Percent of home health episodes of care in which interventions to prevent pressure ulcers were included in the physician-ordered plan of care for patients assessed to be at risk for pressure ulcers. Data from Medicare Outcome and Assessment Information Set (CMS, OASIS-C 2010) as reported on CMS, Home Health Compare in May 2011.
22	**Percent of home health patients with a hospital admission:** Percent of home health care patients who were hospitalized for an acute condition. Data from CMS, Home Health Outcome and Assessment Information Set (CMS, OASIS n.d.), reported in *National Healthcare Quality and Disparities Reports* (AHRQ, 2009).
23	**Percent of caregivers usually or always getting needed support:** Percent of adults who provided regular care or assistance to a friend or family member during the past month and who usually or always received needed social and emotional support. AARP Public Policy Institute analysis of 2009 BRFSS (NCCDPHP, BRFSS 2009).
24	**Legal and system supports for caregivers (composite indicator, scale 0-12):** This indicator is constructed along five components: **Family medical leave.** This component evaluates the extent to which states exceed the federal FMLA requirements for covered employers, covered employee eligibility, length of leave, and type of leave allowed. Scoring: states received scores for the degree to which they exceeded federal FMLA requirements up to a total of 2.9 possible points. Data from *State Family and Medical Leave Laws that Differ from the Federal FMLA*, assembled by National Conference of State Legislatures (NCSL, 2008).
24 continued	**Mandatory paid family and sick leave.** The extent to which states offer additional benefits beyond FMLA to family caregivers, including a requirement that employers provide paid family leave and mandate the provision of paid sick days. Scoring: 2 points for paid family leave; 1 point for statewide mandatory paid sick days, ½ point if not statewide. Data from *State Family and Medical Leave Laws that Differ from the Federal FMLA*, assembled by National Conference of State Legislatures (NCSL, 2008). **State policies that protect family caregivers from employment discrimination.** The extent to which a state (or locality) law expressly includes family responsibilities as a protected classification in the context that prohibits discrimination against employees who have family responsibilities, including providing care to aging parents or ill or disabled spouses or family members. Scoring: 1 point for statewide law prohibiting discrimination, ½ point if not statewide. Data from Local FRD Laws Surveyed, by State and Key Term, reported in *Caregivers as a Protected Class?: The Growth of State and Local Laws Prohibiting Family Responsibilities Discrimination* (Center for WorkLife Law, 2009). **State policies on financial protection for spouses of Medicaid beneficiaries who receive HCBS.** This component evaluated the extent to which the state Minimum Maintenance of Needs Allowance permits the community spouse to retain the federal maximum income allowance and asset resource protections, and whether spouses of HCBS waiver recipients receive the full level of income and asset protection afforded to spouses of nursing home residents. Scoring: 1 point each for using the maximum income and asset protections, and for treating spouses of waiver recipients equivalently to spouses of nursing home residents. Data from AARP Public Policy Institute, *Access to Long-Term Services and Supports: A 50-State Survey of Medicaid Financial Eligibility* (AARP PPI, 2010). **State assessment of family caregiver needs.** The extent to which a state assesses family caregivers for (1) depression, (2) physical health, and (3) the level of strain they experience and use the information (4) to develop a plan of care, (5) to educate and train on skills to provide care, (6) to authorize services to caregivers, and (7) to authorize respite care. Scoring: 0.3 points for each of the seven critical parts of the caregiver assessment (maximum of 2.1 points). Data from *State LTSS Scorecard Survey* (AARP PPI, Scorecard 2010).
25	**Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks):** Number of 16 tasks that can be performed by a direct care aide through delegation by a registered nurse. Data collected from a 2011 National Council of State Boards of Nursing survey on nurse delegation in home settings (NCSBN, 2011).

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Appendix B.4 Glossary

Activities of Daily Living (ADLs): Basic personal activities that include eating, bathing, dressing, toileting, transferring from a bed or chair, and continence. ADLs often are used to measure how much assistance people need and whether they qualify for assistance from a public program or private long-term care insurance.

Adult Day Services: Daytime community-based programs for adults with LTSS needs. Such programs provide a variety of health, social, and related support services in a protective setting.

Aging and Disability Resource Centers (ADRCs): Publicly sponsored entities that are designed to help consumers and their families find information about the full range of long-term services and supports available in their community. They are for people of all incomes and all types of disability. By providing objective information, advice, counseling, and assistance, their purpose is to empower people to make informed decisions and more easily access available programs and services. Similar entities are sometimes referred to as "single entry point" or "no wrong door" systems.

Alternative Residential Settings: Residential settings that are neither private homes or apartments nor nursing homes. These settings include assisted living and small group housing in which services are delivered, usually for no more than 16 residents. An adult care home may be a single-family home in which services are provided to as few as two to three people with disabilities.

Assisted Living: Residences that provide a "home with services" and that emphasize residents' privacy and choice. In many states, residents typically have private rooms or apartment-style units (shared only by choice) with bathrooms and lockable doors. Personal care services are available on a 24-hour-a-day basis.

Care Management: A process for assessing the needs of an older person or adult with disabilities, creating a service plan, and coordinating and monitoring the delivery of services. A care manager may operate privately or may be employed by social service agencies or public programs. Typically, care managers are nurses or social workers.

Chronic Care: Care and treatment given to individuals who have health problems of a long-term and continuing nature. Chronic illnesses generally are not curable, require ongoing treatment, and affect a person's daily life

Cognitive Impairment: Deterioration or loss of intellectual capacity, often resulting from Alzheimer's disease or other forms of dementia. People who have cognitive impairments often require supervision to protect them from injury or harm. Cognitive impairment may affect short- or long-term memory; orientation to person, place, and time; or reasoning capacity.

Consumer Direction (also called Self-Direction): A growing movement to allow participants in public programs to manage and direct their own services, as opposed to having the provision of services managed by a home care agency. Variously called "consumer direction," "self-direction," or "participant direction," this model allows the individual with disabilities to hire and fire a direct care worker. In some cases the participant has control over wages, services delivered, and the schedule for delivering services.

Disability: A limitation in physical, mental, cognitive, emotional, or social activity that results in difficulty performing daily activities or life tasks. Disability may involve not just individual characteristics, but the relationship between the individual and his or her environment.

Family Caregiver: Any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance to an older person or adult with a chronic or disabling condition. These individuals may live with or separately from the person receiving services. Caregivers may provide emotional or financial support, as well as hands-on help with different tasks.

Group Home: Residence that offers housing and personal care services for a small number of residents (often three to eight). Services such as meals, personal care, supervision, and transportation are usually provided to residents by the owner or manager. Residences are usually homelike and may be single-family homes.

Home- and Community-Based Services (HCBS): Services that are designed to support community living and delay or prevent admission to an institution for persons with various disabilities. HCBS can be paid for out of pocket or by private long-term care insurance, or may be funded by Medicaid, state general revenues, the Older Americans Act, or other programs. Medicaid is the primary source of public funding. HCBS can include personal care (help with ADLs), transportation, shopping and meal preparation, home health aides, adult day services, and homemaker services. Assistance with managing medications or money also may be provided.

Home- and Community-Based Services Waivers: Section 1915 (c) of the Social Security Act allows the Secretary of the Department of Health and Human Services to waive Medicaid provisions in order to allow LTSS to be delivered in community settings. HCBS waivers allow states to offer Medicaid beneficiaries an alternative to receiving comprehensive services in institutional settings.

Home Health Agency: An organization that provides home health services supervised by a licensed health professional in the patient's home. Home health agencies may be for-profit or nonprofit entities. Most home health agencies also provide unskilled home care and personal care services.

Home Health Aide (also called Home Care Aide or Personal Care Aide): A person who provides personal care and assistance with household chores and other daily living needs, enabling people with functional and activity limitations to live independently in their homes. These individuals may be hired privately or through a home health agency.

Home Health Care: A wide range of health-related services delivered in a person's home, such as assistance with medications, wound care, and intravenous therapy provided by a nurse; and therapies such as physical and occupational therapy. Such care also may include help with basic needs such as bathing and dressing.

Homemaker Services: In-home help with meal preparation, shopping, light housekeeping, money management, personal hygiene and grooming, and laundry.

Instrumental Activities of Daily Living (IADLs): Routine household tasks needed for independent living, which include using the telephone, taking medications, money management, housework, meal preparation, laundry, and grocery shopping.

Long-Term Care Insurance: Private long-term care insurance is designed to help purchasers pay for the cost of LTSS, the majority of which is not covered by public or private health insurance. Purchasers must pass medical underwriting and continue to pay premiums until they develop a disability. The cost of the insurance is based on the purchaser's age and the amount of coverage selected. Once purchasers qualify for benefits, the policy may pay anywhere from $50 to $500 per day, and purchasers may pay for one year of coverage to lifetime benefits. Most policies sold today cover services delivered in a range of settings, including the home, assisted living, or a nursing home.

Long-Term Services and Supports (LTSS) (also called Long-Term Care): A diverse set of services designed to help people who have disabilities or chronic care needs. Services often include personal care, help with money or medication management, transportation, meal preparation, and health maintenance tasks. The need for services may be of varying duration, but is generally expected to last for at least 90 days. Services can be provided in a person's home, in a community setting such as an adult day center, or in a group residential facility (e.g., small group home, assisted living, or nursing home).

No Wrong Door: The concept of "no wrong door" pertains to a state's system by which individuals access public programs that provide LTSS. Even

though various programs may be administered by different agencies within the state, a no wrong door system facilitates access by developing a single, coordinated system of information, referral, and access to aging and disability LTSS. (See also single entry point.)

Nurse Delegation: The extent to which direct care workers can provide assistance with a broad range of health maintenance tasks. State Nurse Practice Acts usually determine how broad or narrow the range of allowable tasks is in the state.

Nursing Home (or Nursing Facility): Facility licensed by the state to offer residents personal care as well as medical care on a 24-hour-a-day basis. These facilities provide the resident's room and board, as well as nursing care, personal care, supervision, medication, therapies, and rehabilitation. Rooms may be shared, and communal dining is common.

Personal Care: Assistance with activities of daily living (eating, bathing, dressing, toileting, transferring, and continence) that an individual cannot perform without help.

Rehabilitation: Services designed to improve or restore a person's functioning, including physical therapy, occupational therapy, and speech therapy. These services may be provided at home or in long-term care facilities. Some people use rehabilitation of short duration, whereas others require an extended period of rehabilitation services.

Residential Care: The provision of room, board, personal care, and other services delivered in the person's place of residence other than a private home or apartment. Residential care falls between the nursing care delivered in skilled and intermediate care nursing facilities and the assistance provided to individuals in private homes, although residents often receive services similar to those that are provided in a nursing home. It can be broadly defined as the provision of 24-hour supervision of individuals who, because of age or impairments, need assistance with the activities of daily living.

Respite Care: Services designed to allow family caregivers to have time away from their caregiving role. Trained professionals or volunteers may come into the home to provide short-term care (from a few hours to a few days). Alternatively, the person who needs LTSS may spend time in an adult day center or even, in some cases, a temporary stay in a nursing facility.

Single Entry Point (SEP): A statewide system to enable consumers to access all LTSS through an agency, organization, coordinated network, or portal that provides information regarding the availability of such services, how to apply for services, referrals to service providers, and determinations of financial and functional eligibility. These systems also may authorize services from one or more funding sources and perform other care management/care coordination functions. Aging and Disability Resource Centers (ADRCs) may function as, or provide access to, single entry point systems. (See also no wrong door.)

Supplemental Security Income (SSI): A federal income support program for low-income aged, blind, and disabled persons, established by Title XVI of the Social Security Act. States may supplement the basic federal benefit amount.

Transitions: Changes in the setting in which people receive services—between a hospital, a nursing facility, and their place of residence are called transitions. Transitions are important because people are vulnerable to breakdowns in care and poor communication among service providers at these times. Some systems and providers are attempting to improve transitions between settings in order to improve health outcomes for people with chronic conditions or LTSS needs.

About the Authors

Susan Reinhard, R.N., Ph.D., is a Senior Vice President at AARP, directing its Public Policy Institute, the focal point for public policy research and analysis at the state, federal and international levels. She also serves as the Chief Strategist for the Center to Champion Nursing in America at AARP, a national resource and technical assistance center created to ensure that America has the nurses it needs to provide care both now and in the future.

Dr. Reinhard is a nationally recognized expert in health and long-term services and supports policy, with extensive experience in conducting, directing, and translating research to promote policy change. Prior to AARP, Dr. Reinhard served as a Professor and Co-Director of Rutgers Center for State Health Policy, where she directed several national initiatives to work with states to help people with disabilities of all ages live in their homes and communities. Previously, she served three governors as Deputy Commissioner of the New Jersey Department of Health and Senior Services, where she led the development of health policies and nationally recognized programs for family caregiving, consumer choice and control in health and supportive care, assisted living and other community-based care options, quality improvement, state pharmacy assistance, and medication safety. She also co-founded the Institute for the Future of Aging Services in Washington, D.C., and served as its Executive Director of the Center for Medicare Education.

Dr. Reinhard is a former faculty member at the Rutgers College of Nursing. She is a fellow in the American Academy of Nursing and member of the National Academy of Social Insurance. She holds a master's degree in nursing from the University of Cincinnati and a Ph.D. in Sociology from Rutgers, The State University of New Jersey.

Enid Kassner, M.S.W., is Director of Independent Living and Long-Term Services and Supports for the AARP Public Policy Institute. She oversees research and policy development that focus on expanding consumer access and choice to an array of affordable long-term services and supports options, with an emphasis on improving home- and community-based services, supporting family caregivers, and making communities more livable. The mission of the AARP Public Policy Institute is to inform and stimulate sound and creative policies for all as we age. Ms. Kassner's projects have included research on the practices used by state Medicaid programs to ensure the availability of backup home care workers; analysis of state-funded HCBS programs; and a description of the difficulty that consumers have when trying to compare long-term care insurance products.

Under Ms. Kassner's direction, the AARP Public Policy Institute has published *A Balancing Act: State Long-Term Care Reform* and *Across the States: Profiles of Long-Term Care and Independent Living*, in addition to numerous other articles and research reports on LTSS and independent living issues.

Ms. Kassner has more than 25 years of experience in the field of aging as a policy analyst, researcher, author, lobbyist, and speaker on a broad range of issues, including long-term services and supports, Medicaid, and long-term care insurance. She holds an M.S.W. from the University of Maryland and a B.S. from the University of Wisconsin.

Ari Houser, M.A., is the Quantitative Methods Advisor for the AARP Public Policy Institute, as part of the Independent Living and Long-Term Care team. His research focuses on trends in demographics, disability, family caregiving, and use of formal LTSS. He is the lead author and researcher for the *Across the States: Profiles of Long-Term Care and Independent Living* and *Valuing the Invaluable: The Economic Value of Family Caregiving* report series. Prior to joining the AARP Public Policy Institute, Mr. Houser worked at the RAND Corporation on a variety of topics, including occupational health and safety management. He has a bachelor's degree from Swarthmore College and a master's degree in measurement, statistics, and evaluation from the University of Maryland.

Robert Mollica, Ed.D., has an extensive 30-year career in developing state health policy and conducting health and LTSS research and analysis. He managed and coauthored national studies on state assisted living policy and regulation for the National Academy for State Health Policy under grants from the Administration on Aging, the Department of Health and Human Services, the Agency for Healthcare Research and Quality, and the Retirement Research Foundation. Over the years, he has contributed to the steady improvement in how states manage their LTSS options and programs. He provided technical assistance to the National Governor's Association and State Unit on Aging, Medicaid directors, and Area Agency on Aging officials in more than a dozen states. Dr. Mollica has published numerous articles and journal papers on LTSS issues. With Dr. Reinhard, he provided technical assistance to more than 30 states in the Real Choice Systems Change initiative of the Centers for Medicare & Medicaid Services. He also provides technical assistance to Money Follows the Person Rebalancing Demonstration grantees.

Further Reading

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